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ABSTRACT

Some forms of assistive device technology are not available to many disabled children or adults because there is not a centralized system to link the technology with those who need it. This hearing explores ways to promote widespread availability of assistive devices. Examined are types of devices, the costs of such devices, methods of disseminating information about the devices, and the role of the states in coordinating distribution. Included are statements, letters, and supplemental materials from: (1) Congressional Representative Major Owens; (2) government agency representatives from General Services Administration, Office of Technology Assessment, Vermont Rehabilitation Engineering Center, and Central Pennsylvania Special Education Regional Resource Center; (3) private organizations, including Deafpride Interpreting Service, United Cerebral Palsy, Association for Retarded Citizens, American Foundation for the Blind, Electronics Industry Foundation, Self-Help for Hard of Hearing, Council for Exceptional Children, Association for the Advancement of Rehabilitation Technology, and National Easter Seal Society; and (4) private citizens, including a woman with deafness, a young boy with cerebral palsy, and his mother. (JDD)

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HEARING ON ASSISTIVE DEVICES FOR AMERICANS WITH DISABILITIES

ED307766

HEARING

BEFORE THE

SUBCOMMITTEE ON SELECT EDUCATION

OF THE

COMMITTEE ON EDUCATION AND LABOR HOUSE OF REPRESENTATIVES

ONE HUNDREDTH CONGRESS

SECOND SESSION

HEARING HELD IN WASHINGTON, DC, MAY 10, 1988

Serial No. 100-102

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3

CONTENTS

	Page
Hearing held in Washington, DC, on May 10, 1988	1
Statement of:	
Adams, Janice	10
Bibum, Margaret, deputy director, Deafpride Interpreting Service	11
Boardman, Dr. Barbara, senior analyst, Health Program, Office of Technology Assessment	58
Carrol, Mary Ann, United Cerebral Palsy, New York City	95
Cavalier, Dr. Alan, Association for Retarded Citizens, Arlington, TX	73
DeWitt, John, evaluations coordinator, National Technology Center, American Foundation for the Blind, New York City	81
Dormer, Tommy, assisted by Kathleen Abrams, speech pathologist	6
Enders, Alexandra, project manager, rehabilitation engineering delivery program, Electronics Industry Foundation	40
Hahn, Roland, director, Central Pennsylvania Special Education Resource Center	102
Stone, Howard, director, Self-Help for Hard of Hearing	18
Suchanek, Hon. Leonard, Board of Contract Appeals, General Services Administration	14
Weisman, Jerry, Rehabilitation Technology Services, Burlington, Vermont	31
Prepared statements, letters, supplemental materials, et cetera:	
Bibum, Margaret, deputy director, Deafpride, Inc., prepared statement of	13
Boardman, Dr. Barbara, Office of Technology Assessment, prepared statement of	61
Carrol, Mary Ann, prepared statement on behalf of the United Cerebral Palsy Associations, Inc	97
Cavalier, Dr. Al, prepared statement on behalf of the Association for Retarded Citizens of the United States	76
Council for Exceptional Children, prepared statement of	121
DeWitt, John C., evaluations coordinator, National Technology Center, prepared statement of	84
Dormer, Tommy, student, prepared statement of	7
Enders, Alexandra, prepared statement with attachment, on behalf of the Association for the Advancement of Rehabilitation Technology	44
Hahn, Roland T., II, director, Pennsylvania Special Education Regional Resource Center, prepared statement of	105
National Easter Seal Society, prepared statement of	118
Owens, Hon. Major R., a Representative in Congress from the State of New York, prepared statement of	2
Stone, Howard E., Sr., prepared statement on behalf of Self Help for Hard of Hearing People, Inc	20
Suchanek, Hon. Leonard J., Board of Contract Appeals, General Services Administration, prepared statement of	15
Weisman, Gerald, Rehabilitation Technology Services, prepared statement of	34

HEARING ON ASSISTIVE DEVICES FOR AMERICANS WITH DISABILITIES

TUESDAY, MAY 10, 1988

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON SELECT EDUCATION,
COMMITTEE ON EDUCATION AND LABOR,
Washington, DC.

The subcommittee met, pursuant to notice, at 10:10 a.m., in room 2257, Rayburn House Office Building, Hon. Major R. Owens (chairman of the subcommittee) presiding.

Members present: Representatives Owens, Bartlett, and Jeffords.

Staff present: Laurence Peters, Bob Tate, Pat Laird, Jillian Evans, and Gary Granofsky.

Mr. OWENS. The hearing of the Subcommittee on Select Education will come to order.

Today we are considering assistive devices for Americans with disabilities.

Modern technology has leaped ahead of national policy and legislation for people with disabilities. There is an urgent need for the Congress and the Government to run fast and catch up with technology.

Very practical and profitable dividends will result from this long overdue effort to maximize the utilization of technology by Americans.

In addition to creating a better life for millions of individuals, the national economy will benefit from the participation of a new cadre of highly motivated and talented workers. The national treasury will benefit by the taxes paid by this new work force. And the Nation's taxpayers will benefit from the millions of dollars of Social Security payments that will be saved.

This hearing is vital to the process of delivering the people with disabilities in this Nation from the Stone Age neglect of the benefits of technology. The Nation that placed a man on the moon has an obligation to put the state of the art for disabled people within the reach of every citizen who needs it.

The technology of today has freed many disabled people from a life of dependency by enabling even those with the most severe physical impairments to participate fully in education, employment and community activities. Particularly innovative are electronic communications devices which aid those unable to speak in expressing themselves.

Environmental control devices permit mobility impaired persons to operate telephones, kitchen and other household appliances. Spe-

(1)

cially adapted writing aids allow those with limited hand function to control the use of pencils, paint brushes or crayons.

However, many such assistive devices used in educational, recreational and employment settings are not available to most disabled children or adults because there is not a centralized system to link the technology to those who need it. Today's hearing will explore ways to promote widespread availability of assistive devices.

We'll look at how and whether the cost of such devices are prohibitive, and how to go about solving that problem. We'll look at what devices exist, what companies make such devices, how to disseminate information about these devices, and what role the States have in coordinating such services leading to the distribution of these products.

There is legislation pending in Congress which addresses many of these concerns by calling for a comprehensive approach that would allow States to develop the capacity to provide technology and related assistance, create a national information referral network, and promote applied research development and training. This kind of approach would ensure that existing technology and future advances would be more accessible to people with disabilities.

If disabled Americans are to take control of their lives and work toward full democratic participation in society, they must be afforded the means of doing so.

Access to appropriate assistive devices is a key determinant to whether disabled Americans become active participants in society, able to achieve their highest potential in all the areas of life's endeavors, or whether they are forced into helpless dependency.

Disabled Americans no longer have to be prisoners of their impairments. Through the miracles of modern technology, it is possible to bring in a wider range of disabled people who have so far been shut off from a variety of opportunities.

We must do everything that we can to get these assistive devices into the hands of Americans with disabilities so that they can begin to master their own fates.

I yield to the ranking member, Mr. Bartlett, for an opening statement.

[The prepared statement of Hon. Major R. Owens follows:]

OPENING STATEMENT OF CHAIRMAN MAJOR R. OWENS

Modern technology has leaped ahead of national policy and legislation for people with disabilities. There is an urgent need to run fast and catch up with technology. Very practical and profitable dividends will result from this long overdue effort to maximize the utilization of technology by disabled Americans. In addition to creating a better life for millions of individuals, the national economy will benefit by the participation of a new cadre of highly motivated and talented workers. The national treasury will benefit from the taxes paid by this new work force. And the Nation's taxpayers will benefit from the millions of dollars in Social Security payments that will be saved. This hearing is vital to the process of delivering the people with disabilities of this Nation from the stone age neglect of the benefits of technology. The Nation that placed a man on the Moon has an obligation to put the state-of-the-art in technology for disabled people within reach of every citizen who needs it.

The technology of today has freed many disabled people from a life of dependency, by enabling even those with the most severe physical impairments to participate fully in education, employment, and community activity. Particularly innovative are electronic communications devices which aid those unable to speak to express themselves; environmental control devices which permit mobility-impaired persons to operate telephones, kitchen and other household appliances; and specially adapt-

ed writing aids which allow those with limited hand function to control the use of a pencil, paint brush, or crayons.

However, many such assistive devices used in educational, recreational, and employment settings are not available to most disabled children or adults because there is no centralized system to link the technology to those who need it.

In today's hearing, we will explore ways to promote widespread availability of assistive devices. We will look at how and whether the costs of such devices are prohibitive and how to go about solving that problem. We will look at what devices exist; what companies make such devices; how to disseminate information about these devices; and what role the States have in coordinating services leading to the distribution of these products.

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If disabled Americans are to take control of their lives and work toward full democratic participation in society, they must be afforded the means for doing so. Access to appropriate assistive devices is the key determinant to whether disabled Americans become active participants in society, able to achieve their highest potential in all areas of life's endeavors, or whether they are forced into helpless dependency.

Disabled Americans no longer have to be "prisoners" of their impairments. Through the miracle of modern technology, it is possible to bring in a wider range of disabled people wo have so far been shut out from a variety of opportunities.

We must do everything we can to get these assistive devices into the hands of disabled Americans so that they can begin to "master their own fates."

Mr. BARTLETT. Thank you, Mr. Chairman.

I particularly want to thank you, Chairman Owens, for holding these hearings, so that the subcommittee can look at ways to get technology out and look at this technology itself. We want to get this technology to every disabled person who can benefit from that technology.

This technology exists, but it is neither widely accessible nor widely known.

I hope that the testimony from this hearing will provide us with at least some of the answers on how to obtain technology related assistance for people with disabilities. I don't believe that the answer to the problem is to create another bureaucracy at either the Federal or the State level, though.

Congressman Jeffords and I are working on another approach, which we have shared with Chairman Owens and are working on with him and with this subcommittee. This is an approach that would be in a piece of legislation that would establish and expand the existing capacity of agencies and other entities within States to help persons with disabilities acquire information about technology and obtain assistance in purchasing, using, maintaining, adapting and upgrading technology products.

Our proposal's goal would be to provide direct assistance to States, establishing a national information and referral network, support research and development activities, recognize and promote initiatives in the private sector, and provide a demonstration loan program for persons with disabilities to obtain a job, or for employers who wish to hire persons with disabilities.

These activities are essential if the Federal Government is going to impact the use of Federal and non-Federal dollars in a complimentary way which promotes access to technology for persons with disabilities.

The role of the Federal Government in providing technology related assistance to persons with disabilities should be to increase coordination among existing services, systems and manufacturers that currently provide assistance to persons with disabilities.

If the Federal Government is going to serve as an effective catalyst, a comprehensive approach is necessary if we want to reach every person with a disability that could use technology related assistance.

I want to welcome all of our witnesses to the subcommittee today, and I'm confident that the testimony that we hear today will be able to tell us if we're moving in the right direction.

I'm particularly pleased that Dr. Al Cavalier, a fellow Texan, is testifying before us today. Dr. Cavalier is the director of bioengineering at the Association for Retarded Citizens in Arlington, Texas. He and his staff have been instrumental in taking existing technology and adapting it to the needs of people with multihandicaps, especially those with mental retardation.

One of the problems that exist in providing technology to people with disabilities is that many providers do not know what exists, or how to adapt a piece of equipment to a particular individual need. Dr. Cavalier will demonstrate today how adapting existing technology can open new doors for mentally retarded people and allow them to lead a more independent and productive life.

Information about and access to technology can have a dramatic effect on a disabled persons' life. For most of us, technology makes things easier, but for persons with disabilities, technology makes things possible.

Technology allows a person with disabilities to transcend limitations and become a full participant in their education, their job, and their community. Technology can provide eyes for persons with visual impairments, ears for the hearing impaired, and a voice where there was once silence.

We as lawmakers, parents, providers, teachers, physicians and employers must find the key to unlock the door to technology accessibility.

In addition, providers, teachers, and employers must be trained in the procedures to use and maintain assistive devices. Technology is useless to people with disabilities if no one can teach them how to use it, maintain it, or upgrade it.

This hearing is the beginning of that process, and I hope that witnesses can provide the subcommittee with the information we need to help people with disabilities obtain technology, which will improve their lives.

I thank the Chairman for the time.

Mr. OWENS. I yield to Mr. Jeffords for an opening statement.

Mr. JEFFORDS. Thank you, Mr. Chairman, and I deeply appreciate the holding of these hearings.

Many of our colleagues took an important step on April 29 when we introduced the Americans with Disabilities Act of 1988. The ADA will cause many of the forms of discrimination against persons with disabilities to be lessened and eventually eliminated.

This hearing today is another important step. We will have an opportunity to learn about, and to share with others, the positive effects of technology on the lives of persons with disabilities. Tech-

nology will play a critical role in removing barriers associated with handicaps and discrimination.

Thus, now is the right time to collect the facts about technology and to develop the right Federal role in promoting and understanding the availability and use of technology by persons with disabilities.

We know some facts already, and have used them to shape a tentative Federal role in the proposed legislation, the Technology Related Assistance for Persons with Disabilities Act.

The testimony that we receive today will let us know whether or not we are on the right track.

Would it be appropriate to establish a competitive grant program for States to assist service providers to increase their capacity to help persons with disabilities acquire the use of technology?

How important is a national information and referral network in technology? How can the Federal Government encourage greater private sector involvement in research and development in limited markets? Would it be useful to educate employers in the benefits of technology in the workplace, and is a revolving loan program a viable way to increase funds for the purchase of technology by persons with disabilities and their employers?

As you know, we have tackled these central questions in our draft legislation. I anticipate that the testimony that we receive today will help strengthen our draft and make us able to work with our Senate colleagues to be able to introduce and pass technology legislation during the remaining days of this Congress.

We could choose to wait, or to take a piecemeal approach. We could assume that Federal intervention is not needed, and we could assume that the need for technology by persons with disabilities is overstated.

If we wait, will we receive credit for caution? If we respond with limited solutions, will we be viewed as advocates for equity? If we say targeted Federal assistance and direction is not part of the answer, will we be part of the solution?

If we contend that the magnitude of the need is a reflection of speculation and not fact, will our credibility be unchallenged?

Quite simply, the answers are no.

Mr. Chairman, by holding this hearing, you have given us an opportunity and a basis for momentum, and a challenge to deliver. Working together, we can.

Mr. OWENS. Thank you, Mr. Jeffords.

Our first panel consists of Mr. Tommy Dormer, Ms. Janice Adams, Ms. Margaret Bibum, the Deputy Director of Deafpride, Judge Leonard Suchanek, and Mr. Howard Stone.

Will you please take seats?

Most of you have submitted written testimony, and that written testimony will be entered in its entirety into the record. We hope that you can confine your oral remarks to just the highlights of your testimony.

There will be bells ringing after 7 minutes, and we'd like you to conclude your testimony at that time.

Our first witness is a very busy young man, and will have to leave shortly after he testifies. We're going to take his testimony

and question him first, and then continue with the rest of the panel.

Mr. Tommy Dormer is assisted by his mother, Mrs. Dormer.

STATEMENT OF MASTER TOMMY DORMER, ASSISTED BY KATHLEEN ABRAMS, SPEECH PATHOLOGIST

Master DORMER. Hi.

My name is Tommy Dormer. I am in the first grade. I talk by using this machine. Technology helps me do my schoolwork. I would like to tell you my story that I wrote with the computer. The title is: "The Computer Helps Me."

The computer helps me to think. I like the computer. It helps me to write and to do my schoolwork. It helps me a lot. I love the computer.

I need a computer to do my work. I can play games on the computer. I can draw pictures on the computer. I can make something and give it to a friend.

Please help other children like myself who cannot talk. Now my mother will tell you something.

Mrs. DORMER. Good morning.

My name is Veronica Dormer. This is my son, Tommy Dormer.

Mr. OWENS. Could you sit and have a chair next to the microphone?

For those of you in the back who couldn't hear, Tommy has told us that his name is Tom Dormer, and he's in the first grade. He says, "I talk by using this machine. Technology helps me do my schoolwork. I will tell you a story that I wrote with the computer. The title is, 'The Computer Helps Me.'"

The computer helps me to think. I like the computer. It helps me to write and do my schoolwork. It helps me a lot. I love the computer.

I need a computer to do my work. I can play games on the computer. I can draw pictures on the computer. I can make something and give it to a friend.

Please help other children like myself who cannot talk. My mother will tell you something."

And now, Mrs. Dormer.

Mrs. DORMER. Yes.

This is my son, Tommy Dormer.

Eight years ago, when the neurologist called me into his office and told me that Tommy has cerebral palsy, and would not have total control of his body, at the time I felt cheated.

Well, today——

Mr. OWENS. Would you move the mike a little closer?

Mrs. DORMER. Well, due to technology Tommy now writes me notes. He writes his favorite cousin letters. He tells me who his best friend is. He cheered for the Redskins when they won the Super Bowl.

The best thing of all is when Tommy, who cannot talk, tells me "Mommy, I love you."

Well, there's a lot more that Tommy would be able to do if he could just get the things that he needs.

Thank you.

[The prepared statement of Tommy Dormer follows:]

STATEMENT OF TOM DORMER AND HIS MOTHER, MONTGOMERY COUNTY, MD

Tom Dormer:

Hi. My name is Tom Dormer. I am here on behalf of all children who need technology. I am in the first grade. I talk by using this machine. Technology helps me do my school work.

I will tell you a story I wrote with the computer. The title is: *The Computer Helps Me*

The computer helps me to think. I like the computer. It helps me to write and to do my schoolwork. It helps me a lot. I love the computer.

I need a computer to do my work. I can play games on the computer. I can draw pictures on the computer. I can make something and give it to a friend.

Please help other children like myself who can not talk. My mother will tell you something.

Mrs. Dormer:

Eight years ago when the neurologist called me in his office and told me my child had cerebral palsy and he would not have total control of his body, I felt cheated.

Well, today, due to the use of computer technology:

He now writes me notes
He writes letters to his favorite cousin
He tells me who his best friend is
He cheered for the Redskins when they went to the Super Bowl

The best thing of all is when my child who cannot talk says, "Mommy, I Love you!"

Without the use of technology, how else could he have done that.

Well, there is a lot more Tommy is capable of doing if we could afford to get him the equipment he needs.

Thank you.

Mr. OWENS. Thank you.

Now, Tommy, we hope that you grow up and write books.

What is your favorite television show?

Mrs. DORMER. His favorite television show is The Cosby Show and Alf.

Mr. OWENS. What's your favorite football team?

Master DORMER. The Redskins. Go.

Mr. OWENS. The Redskins. [Laughter.]

Mrs. Dormer, what is the cost of this device? Speak into the mike, please.

Mrs. DORMER. This is over $3,000. It was bought by the Society for Underprivileged Children. They were very generous.

Mr. OWENS. Now, the computer here also——

Mrs. DORMER. No, this is his voice.

When it's attached to the computer in school, this is when he writes and draws or does other things that a regular computer would do.

But without this attached to it, it's not able to do that.

Mr. OWENS. Did you opt to pay any portion of that cost?

Mrs. DORMER. Not for this, no.

Mr. OWENS. But what would a computer cost?

Mrs. DORMER. I'm not sure of the price of computers. They're in the thousands of dollars.

They have one that they have an hour a day on, in school. That's what he used.

This is what he uses at home and in school.

Mr. OWENS. What is the possibility of his getting a computer for home use?

Mrs. DORMER. Right now, the possibilities are bleak. We cannot afford it, and there is no organization out there that would help us, if you just make a little over $8,000. We just can't afford the prices of this computer.

Mr. OWENS. There's no place where you can get help, you say, because——

Mrs. DORMER. No, not with what I make.

I don't make a whole lot, but if you're a little over $8,000, they think you're above the poverty bracket.

You don't get help that way. You have to be really poor to get anything.

His chair was bought through my insurance company, which paid 80 percent. I paid the other 20 percent of that, and that's talking about 20 percent of $7,000.

Mr. OWENS. You paid 20 percent of $7,000?

Mrs. DORMER. Yes.

Mr. OWENS. I see.

Any questions from panel members?

Mr. BARTLETT. I have several questions, Tommy.

My first question is, I hope someday you'll consider rooting for the Dallas Cowboys. [Laughter.]

They're a good team, also.

Master DORMER. Go Redskins. [Laughter.]

Mr. BARTLETT. That was Go, Redskins, Go.

Mrs. Dormer, I wonder if you could elaborate a bit. How did you find this device; where did you—how did you determine that this was the device that Tommy needs? Were there other devices that you considered and were able to compare this kind of adaptive device versus other things that are available?

Mrs. DORMER. The psychologist who tested Tommy for placement in Montgomery County Public Schools——

Mr. BARTLETT. On the school staff?

Mrs. DORMER. Yes.

He found out at the time that he needed some sort of communication. He had difficulty testing him, even though he was capable. So we went out to seek aid in getting him a device, and that's when he went to the Society for Underprivileged Children, and they bought the device.

Mr. OWENS. Did the Society sit down, or the psychologist, and walk through a catalog or some kind of engineering with you? Did you consider other devices? Or did someone just tell you that this was the one, and you got it?

Mrs. DORMER. He told me what it was doing, and I was very pleased. I left it entirely up to him.

When he got the machine, he brought it to me and showed me all the things that it could do. I was very pleased with that.

Mr. BARTLETT. This was the Society for Underprivileged Children, or the psychologist?

Mrs. DORMER. The psychologist.

He went through the Society for Underprivileged Children.

Mr. BARTLETT. So, so far as you know, you don't know of any other devices? You didn't yourself consider or examine other devices that would have——

Mrs. DORMER. I only knew about the computer in school at the time. But the computer could not talk.

I didn't know about these devices until they put them to me.

Mr. BARTLETT. So this is the only communication device that you considered, then, as far as—the psychologist told you that this was what you needed, and this was what you got?

Mrs. DORMER. That's what he got.

Mr. BARTLETT. That's what he got.

Mrs. DORMER. But in the school, they're looking at other devices right now, because there is a lot more out there since this talker.

Mr. BARTLETT. Was there a catalog? Did the psychologist have a catalog or some kind of network? Do you know?

Mrs. DORMER. With this machine, you only have two types right now. You have the Light Talker—that's what Tommy has—and you have the Touch Talker. He can't use the Touch Talker because he can't use his hands.

Mr. BARTLETT. The—you paid, tell us again how you financed it. The Society financed the entire thing, but you paid 20 percent of the wheelchair?

Mrs. DORMER. The wheelchair is what his physical therapist and his orthopedic doctor thought he needed, so they submitted that to me, and I submitted it to my insurance company. They agreed yes, he needs it, and they paid 80 percent after my $100 deductible. But the other 20 percent is up to me.

Mr. BARTLETT. That therapist was paid for by whom? The insurance company? Or did you go out and hire the therapist?

The therapist who recommended the wheelchair.

Mrs. DORMER. This was at the Kennedy Center, where he goes for therapy. We go once a month, or sometimes twice a month. That's in Baltimore.

Mr. BARTLETT. When you considered this wheelchair, were there other types of wheelchairs that you looked at? Did you see any kind of a range of choices?

Mrs. DORMER. Yes.

There were other types of wheelchairs, but they're not moved in the same way as Tommy's moves.

They are hand devices or maybe mouth devices. He generally uses his head. That's the type that we thought was best for him.

We're talking like three years ago, maybe four.

Mr. BARTLETT. So you did see some kind of a range of other options with the wheelchairs.

Mrs. DORMER. With the wheelchairs, yes.

Mr. BARTLETT. Were you able to see that wheelchair before you bought it?

Mrs. DORMER. Yes.

Mr. BARTLETT. Where did you see it?

Mrs. DORMER. We went into the—it was Fairfield Medical that we went into. They had one on display at Kennedy Center, and it wasn't the same sort that Tommy needed, so we went into Fairfield Medical, which was in Baltimore at the time, and they showed me the wheelchair.

But Tommy didn't have the controls and all that on it. But they showed us at this age, this is the type you would need for now, and then you would grow up in it.

Mr. BARTLETT. Back on the—you don't have a home computer. Then Tommy can't talk at home?

Mrs. DORMER. He talks at home, but he just can't write.

Like, doing his homework, I help him. I sit with him and write for him. He tells me what number on his Light Talker, and I write it. Sometimes, if he's not fast enough, I'll put the numbers out.

If he had a computer, he could sit and do his own papers on that computer.

Mr. BARTLETT. If some agency were to make available to you a low-interest loan, that you would pay back over 5 years or something like that, would that make the purchase of a home computer available to you?

Mrs. DORMER. That would be very helpful.

Mr. BARTLETT. Thank you, Mr. Chairman.

Mr. OWENS. Mr. Jeffords?

Mr. JEFFORDS. Mr. Chairman, I just have one comment.

Tommy, your smile has let us know what it's all about and has given me the incentive to move forward on our legislation.

Thank you so much.

Mr. OWENS. My final comment is go, Tommy, go. [Laughter.]

We want to thank you both, and we understand that you will have to leave now.

But we appreciate your appearing here this morning, very much.

Our next witness is Ms. Janice Adams.

Ms. Adams?

STATEMENT OF MS. JANICE ADAMS

Ms. ADAMS. I'm not sure if you can understand me. If you can't understand me, please stop me. All right?

Mr. OWENS. Yes, we understand.

Ms. ADAMS. On behalf of other deaf persons, and myself, I'd like to talk with you about different assistive devices. I have one here. This is called the Pal Operator. This is a phone device that is used by deaf people to talk on the phone.

There is a mouthpiece here, that's where you put the phone down. Then you tell them to turn it on, and the operator will come on and you hear it.

This machine can be used for communication. I can read out things from people who know how to type, and I can read what they send to me. This is a good way to communicate for people who don't know sign language because I can use it for the phone, but I have to turn the mode to telephone. It has to be put on telephone mode.

There's one problem. This machine is very, very expensive. It costs $5,500, and only one company in this country makes TTY's like that. There isn't enough competition. Most deaf people can't afford it.

People would like to see the Government help people buy TTY's like that. It provides contact with the outside world and enables us to do business on the phone, and other things.

How many of you never use the phone? No one. We want to use the phone, too.

There are other devices that I would like to tell you about, such as the computer, such as an IBM computer for the blind. You have to have a regular computer, and then you can buy another machine that has a braille display, and that braille display costs about $3,500, plus the computer, plus the software that's needed to make it work. So you can see that that is a tough bill to pay.

Do you have any questions?

Mr. OWENS. We'll take questions later on.

Remain seated, and we'll take questions when the panel is finished.

The next panelist is Ms. Margaret Bibum.

STATEMENT OF MS. MARGARET BIBUM, DEPUTY DIRECTOR, DEAFPRIDE

Ms. BIBUM. Good morning.

I'm going to talk with you through an interpreter.

I am the deputy director of Deafpride, Incorporated, located here in Washington, D.C.

This is a community based organization working for the human rights of deaf people and their families.

This morning, my testimony will focus on the poor and the working poor deaf people.

Our technology has had many, many improvements during these last few years, and I won't go into depth as far as the different types of technology. We've seen some of that discussion this morning.

As Janice just said, it is expensive to be deaf and blind. It is also expensive to be deaf. That's been our regular expression. It is expensive to be deaf.

We have to buy a hearing aid, a TTY, a TV decoder, a special alarm clock that can be a type of vibrating alarm clock or a flashing light, a baby cry light, a door light, a phone light, and so on and so on.

Even for deaf people who have well-paying jobs, this can be an additional burden. For deaf people to use a telephone, we must have a TTY. For many deaf people who are poor or who are in poor families, many times that expense is just too much and not able to be afforded.

Many people are isolated from the community and are not able to call for emergency assistance, contact hospitals or schools, or associations.

A TTY can cost anywhere—the cheapest one—from $150 to $1,000, depending.

One of Deafpride's programs is called Project Access. That works primarily with low-income black deaf women and their families here in Washington, D.C.

The Project Access staff focuses on health care accessibility. Our work with black deaf women is on a daily basis, and we see many, many confrontations with access into these systems, because of a person's financial status.

I think that the best way to guide you through a black deaf woman's experience, as she becomes pregnant, for example.

The woman is pregnant. She goes to a government health-care center here in Washington, and that health center is pretty terrific. It provides accessibility, it provides TTY, and interpreter services. A deaf person advocate is on staff there, and you would think, Great. Wonderful.

But, when the deaf woman goes to her own home and tries to contact her doctor because she feels sick or she needs to discuss something about her pregnancy, she's stuck. She doesn't have a TTY herself. It's ironic: the health center may have a TTY, but she doesn't have one. How is she to contact her health care provider?

At the same time, that deaf woman may need to be abreast of information about health care, various issues, programs on TV related to health care issues—that would sound great. But to see this TV program related to health care issues, related to AIDS, related to pregnancy or whatever—her TV does not have a decoder. That TV decoder may cost $199. Maybe that doesn't sound a lot—it's not as expensive perhaps as some of the Braille TTY equipment—but that can be a very extraordinary expense for a low-income person.

That deaf woman has given birth. She has to buy a baby cry light. So many times, that woman is not able to afford up to $140. You may think again that is a very small expense, but for many women, they're not able to afford it.

Where does this deaf woman live? Does her front door have a flashing light for the doorbell? No, she can't afford it. Does she live in a security building? How does she know who's flashing the light, who's pressing the doorbell downstairs?

Here in Washington, D.C. it's said that the landlords must provide for a doorbell a flashing light, a visual smoke alarm. But many deaf people don't know about this law. They are not aware of their legal rights.

What I've tried to do in this short time that I have here this morning is to lead you through the life of a typical deaf woman here in Washington, D.C.

She is trying to get access. Some deaf people do have the technology. I have a TV decoder. I have a flashing light on my doorbell. I have an alarm, a vibrating alarm clock. But still, again, that's not an exactly perfect situation.

The TTY is fine. I'll call a hospital. Most hospitals will have their TTY's in the emergency room. They don't have a TTY at the information desk. Just last week my friend had to be carried to the hospital. How was I to contact the hospital? I had to contact an interpreter who contacted the hospital.

Most—you know about the law 504, which provides that Federal agencies and those that receive Federal funding are to provide access. But so many hospitals and other facilities do not provide access, or their access is very limited.

Related to the TV decoder, so many of our programs now are captioned, but that's not enough. You understand, my local news program—I have to wait and stay awake until 11 at night to see Channel 7 with the captions. I would be very tired in the morning when I wake up, but this is here in my capital city.

I realize this morning that my testimony is very condensed. I could sit here for a week and explain really in depth what life is

like for us. But I want you, please, to keep in mind that we do have this wonderful technology.

But for many of us, who are poor, who are very limited in income, there is still—although we have this wonderful technology—many of us are not able to get these things.

When you consider your allocation of funds, please keep in mind the access needs of the poor and the working poor deaf people in this city and all over the country.

Thank you.

[The prepared statement of Margaret Bibum follows:]

TESTIMONY OF MARGARET BIBUM, DEAFPRIDE, INC.

Good morning. My name is Margaret Bibum, Deputy Director of Deafpride, Inc. Incorporated in Washington, D. C. in 1972, Deafpride is a community-based organization which works for the human rights of Deaf persons and their families. The organization's empowerment and advocacy programs bring together a diversity of people to work for individual and institutional change. Today, I am here to speak for Deafpride's constituency and for myself as a Deaf woman. My husband and son are both Deaf.

Technology has made many, many advances over the past few years. I will not detail all the different technological miracles that are available today, or still being developed. In my testimony today, some of my focus will be on the needs of a specific segment of the deaf community, poor or working poor Deaf persons. They may include Deaf children, Deaf parents or Deaf senior citizens.

A familiar quote in the deaf community is "it is expensive to be Deaf". By the time we have bought hearing aids, TDD's, television decoders, special alarm clocks, baby cry lights, door lights, smoke alarms, etc., one can understand why. Even for those Deaf persons who have well-paying jobs, these assistive devices are an extra expense.

For the Deaf person to use the telephone, he or she needs to purchase a TDD (Telecommunications Device for the Deaf). For many poor or working poor households especially, this often is beyond the family budget. Therefore the Deaf person is isolated from the community. He is unable to call for emergency assistance, hospitals, schools, social service agencies, their place of employment and so the list goes on. TDDs can cost anywhere from $150 to $1,000, depending on its capacity.

Television, for many years, has been off-limits to Deaf persons. As a Deaf person, I am not able to follow television programs without use of a Decoder. Today when so many TV programs are closed captioned, I am able to watch these programs with my decoder. It means that my family has more access to information as well as be able to enjoy shows and news programs, along with hearing people. Especially for my son, I see the advantages of closed-captioning on his development in reading and writing English. Also, as a family, we are able to watch captioned programs such as the CBS news at 6:30 p.m. However, for too many families, the decoder is not available because it costs around $199, way out of reach for many families on fixed incomes.

In its final report, published February, 1988, the Commission on Education of the Deaf states that too many Deaf persons do not have access to captioning. It further states that each television set should be fitted with a decoder module, so that all persons can receive close captioning. The FCC should mandate that manufacturers include the decoder module in all new TV sets. It has been recommended by the COED that present federal funds which are allocated to decoder development should instead be used for the distribution of free decoders to persons who are deaf.

One of Deafpride's programs, Project Access, works with primarily low income Black Deaf women and their families in the District of Columbia. Project Access staff work in the area of health care access. In our work with these Deaf women, we often encounter many barriers to total access because of the deaf person's financial status.

Let me take you through a health situation involving a Black Deaf woman in Washington, D.C. The woman, who is pregnant, is a patient at a government health center which is providing accessible health services through the provision of sign language interpreters and a Deaf patient advocate. So far, wonderful! However, when that Deaf woman is in her home, she needs to contact her doctor at the health center because she is feeling sick. The health center has a TDD. However, the Deaf

woman herself does not have a TDD. How, then, can she communicate with her doctor?

The deaf woman is instructed, during her prenatal care, regarding the importance to be informed on various health-related issues. She is encouraged to read and watch television programs relating to health. However, she does not own a decoder for her TV set. Yet, another barrier to access because of low income.

By now, the Deaf woman has given birth to her baby. She is told she needs to have a baby cry signal to alert her when her baby cries. This is yet another additional expense.

Let us think about where the Deaf woman lives. Does her front door have a flashing light? If she lives in a security building, how does she know if someone is ringing her door bell? By law, in D.C. the Landlord of the dwelling unit shall "provide a visual alert system in which a deaf or hearing-impaired person resides." This was signed into law by the Mayor on December 10, 1987. For many Deaf persons, however, this law is largely unknown, so that they are once again unable to receive their full legal rights to access.

What I have just done is try to help you "experience" what many Deaf residents of the District of Columbia face daily. However, some deaf persons, including myself, do have a TDD, Television decoder, flashing door and phone lights, vibrating alarm clock, etc. That sounds wonderful! But is it so wonderful? Let us look at the TDD situation. Almost all hospitals in the District of Columbia have TDDs. However, it is often placed in their emergency rooms. The Information Desk often does not have a TDD. My Deaf friend was recently rushed to a hospital here in D.C. I had to call that hospital through an interpreter to find out where her room was and how she was progressing.

I have a television decoder at home. Many programs are captioned, but many more are not. True, I can watch CBS captioned news at 6:30 p.m., however, to watch the local news captioned, I have to stay awake until 11 p.m. to watch Channel 7!!

My rented townhouse in D.C. is equipped with a door light and visual smoke alarm system. Maybe the reason for this is because my Landlord is Deaf!!

All government agencies, both Federal and local, must be mandated to have TDDs in their offices in order that Deaf consumers can call them. We know Section 504 of the 1973 Rehabilitation Act mandates all federal agencies to provide access to their programs. However, Congress should watch that this law is being adhered to.

I hope that, through my testimony this monring, I have shared with you many of the problems that Deaf persons face, despite sophisticated technology. I am asking that Congress should always consider the access needs of poor and working poor Deaf persons when allocating federal funds. Deafpride is always ready to assist in any way possible to ensure that Deaf persons receive their basic rights to live in a just and equitable society.

Thank you.

Mr. OWENS. Thank you.

Judge Leonard Suchanek.

STATEMENT OF JUDGE LEONARD SUCHANEK, BOARD OF CONTRACT APPEALS, GENERAL SERVICES ADMINISTRATION

Judge SUCHANEK. It's a pleasure to be with you this morning.

I have submitted a lengthy statement of some 10 pages, which I invite you to peruse.

Let me take just a couple of minutes to summarize that statement. In the first few pages, I discuss a recent law that was passed by Congress relating to the accessibility of electronic equipment. This discusses the guidelines for Federal procurement that are being issued in compliance with that law—guidelines that are being promulgated by the General Services Administration and the Department of Education.

On pages four and five of the paper, I point out that although accessibility to electronic equipment is essential, and extremely important for the disabled, that it's necessary to look at the entire environment. Specifically, I state—and I'll read this to you: "We need to reeducate"—this is referring to the Government—"personnel

specialists in areas such as job placement, assistance and classifications."

The point that I'm making is that change must come from more than one direction. Technology is only one of the issues affecting employment of the handicapped.

On page six, I refer obliquely to my own experience at the Board of Contract Appeals. When I was appointed Chief Judge of the General Services Administration, I was determined to make the General Services Administration Board of Contract Appeals into the finest administrative judicial tribunal in the Federal Government. And so, it was important for me to bring into that office all of the advances in technology, not only for everyone else, but as far as I could for myself as well.

In fact, our office was the first office—you'll be interested in this—in the General Services Administration to become fully automated. That was in 1980 and 1981.

Because of my own experiences, during the coming years, in 1983 I began a series of discussions with various officials in the Agency, and as a result of those discussions, the Administrator of the General Services Administration in early 1984 established what became known as the Inter-Agency Committee for Computer Support of the Handicapped, and appointed me chairman of that committee. Incidentally, I'm still chairman of that committee.

Since that time, since March of 1984, the committee has grown. It is now the largest interagency committee in the Government dealing with the disability area. It has 24 member agencies. All of the representatives on this committee are from the senior managers in the ADP area of these various agencies.

I discuss at length the goals of the committee. If you take a look at pages seven and eight, we think that as a result of the work of the committee, we've made tremendous advances in the Government.

Finally, on page 10, I refer back again—actually at the bottom of page 10—to the idea that technology is not a complete answer. I speak specifically to an initiative begun by the committee on conjunction with the Office of Personnel Management last October. I state that since October, we have been working with the Office of Personnel Management to improve policies and procedures relating to the employment of personal assistants for disabled Government employees.

I'll be pleased to answer any questions that you may have.

[The prepared statement of Hon. Leonard J. Suchanek follows:]

TESTIMONY OF JUDGE LEONARD J. SUCHANEK

Handicapped Americans have come a long way, from the days when the blind peddled pencils in subway cars, the deaf exchanged sign language cards for pennies and those confined to wheelchairs did not "work" at all. Today, technology has provided a means to place the disabled on the employment rolls instead of on the welfare rolls.

It is our hope that one day, the technology that enables a handicapped person to function in the work place will be as common as the word processor, the personal computer, or the typewriter. We must convince employers that hiring handicapped workers does not mean reduced productivity.

We can do it! We are well on the way to this goal with the passage of Public Law 99-506. This law is the re-authorization of the Rehabilitation Act of 1973 which contains a new section, Section 508, that addresses electronic equipment accessibility.

This new section is tremendously important. I shall quote just two paragraphs to you.

The first paragraph says this: "The Secretary [of Education], through the National Institute on Disability and Rehabilitation Research and the Administrator of the General Services [Administration], in consultation with the electronic industry, shall develop and establish guidelines for electronic equipment accessibility designed to insure that handicapped individuals may use electronic office equipment with or without special peripherals."

Now, this is the second paragraph: "Beginning after September 30, 1988 the Administrator of General Services shall adopt guidelines for electronic equipment accessibility established under subsection (a) [which is the first paragraph I quoted] for Federal procurement of electronic equipment. Each agency shall comply with the guidelines adopted under this subsection."

This tells us that all future federal government procurements of electronic equipment must include the guidelines for accessibility. If the guidelines are effective, then the procurement of accessibility technology will be an everyday occurrence because accessibility will become a consideration in every procurement.

I urge you to study the initial guidelines. As you review them, note that they are merely a draft, just a beginning, and are currently under review by government, industry, and academia.

All of us, as Americans, have a vested interest in these guidelines. Government is relying on technology to increase productivity, and many fear that accessibility could stem its growth. Business worries about separate product lines for the Government, increased demands, research and development, and the potential of lost business. The disabled community sees the guidelines from a different perspective. It is not enough to have guidelines which really don't stretch the state of technology or expand the scope of technology from just the IBM personal computer and its clones to the full range of information technology. Federal employees can already obtain accessibility aids to achieve reasonable accommodation. If the guidelines don't establish a foundation for full access to all information technology in the work place, then they don't really do much good at all.

Currently, the agencies responsible for the guidelines, GSA and the Department of Education, are collecting comments from selected reviewers. Within the next several months GSA will publish a draft of the new Federal Information Resources Management Regulation, FIRMR, providing procurement guidance from GSA. It is expected that the draft FIRMR will generate a great deal of comment. All of the comments will then be analyzed and a revised guidelines document will be prepared.

Up to this point, I have focused on the issuance and effect of the guidelines because our ultimate concern should be with employment. I am convinced that the guidelines can broaden the spectrum of employment possibilities for the disabled, and open up this untapped resource to meet the needs of the Government in the future. I am not so much concerned with the 1980's as the 1990's. If the guidelines are effective, then the computer designs already on the drawing board will incorporate these new technologies and employment prospects will improve. This will benefit employment applicants with disabilities and the Government as a whole. If the guidelines are too weak, then the gap between the vendors of accommodation aids and major computer vendors will grow. This is because technological breakthroughs will lead the major vendors on paths that fail to accommodate the needs of handicapped users. Personally, I am confident. I have been involved with policy issues relating to users with disabilities and computers since 1983. I have seen a great deal of good work done. Senior federal managers are interested, and I believe the final guidelines and FIRMR regulations will lead the way for the public sector. The federal community should be a model for the private sector as well as for state and local governments.

Despite this progress, we still have a long way to go. Regulations on the books don't do the job alone; they are implemented by people. We must interest the first and second line federal manager in employing users with disabilities. Already, agencies like SSA and IRS and companies like IBM have recognized that hiring handicapped individuals makes good business sense. That's the message we must preach. But it is not enough. We need to re-educate personnel specialists in areas such as job placement, assistance and classification. The point I am making is that change must come from more than one direction. Technology is only one of the issues affecting employment of the handicapped. We must create the environment where the federal manager or the business manager feels confident about the decision to hire a handicapped worker.

Also, remember we still face the challenge of educating handicapped users of the possible impact of technology on their current jobs as well as on their career potential. The technology is there today. It is to a disabled jobseeker's benefit to understand and try the accommodation technology relating to his disability. The ability to say "I can do that job" will impress potential employers and will bolster the jobseeker's confidence.

You will be hearing more about the guidelines in the next several months. They will be the focus of the Interagency Committee for Computer Support of Handicapped Employees computer conference in October 1988. I personally invite you to attend. I can guarantee that you will be treated to a spirited exchange of ideas.

Let me now brag a little about the achievements of the GSA in developing technologies for users with disabilities. At GSA we use the term, "computer accommodation," to describe this work.

I am proud to say that the initiatives for computer accommodation at GSA originated at the GSA Board of Contract Appeals. When I first began using computers to produce Braille I did not have an appreciation for the lack of policy and technical initiatives in the area of computer accommodation. Yet as recently as 1984 there were no established policies. This is not to say that computer accommodation did not exist. There were several agencies that were involved in computer accommodation at that time; but it was only on a case by case basis. There were no information exchanges, support mechanisms, or procedures. So, in most cases, it was a continual rediscovering of the wheel. Each manager had to do his own research, fight the struggles of procurement, and provide his own technical support and interface to the equipment already used by the agency.

In 1983 I had several meetings with high level GSA officials to discuss the status of computer accommodation. As a result of these meetings, in 1984 the Administrator of GSA issued two orders creating the Interagency Committee for Computer Support of Handicapped Employees and the GSA Clearinghouse on Computer Accommodation, which is known by the acronym COCA. Since 1984 I have served as Chairman of the Interagency Committee.

The goal of the Committee is to advance the management and use of information technology in order to promote the productivity and achievement of disabled employees.

The Committee advises GSA on government-wide policy relating to the development and use of information technology to benefit disabled employees. The Committee also sponsors activities to induce federal agencies to adopt information technology that will encourage the hiring of the handicapped, and once hired, improve their productivity.

Twenty-four federal agencies and departments comprise the current membership of the Committee and it is still going. The representatives to the Committee are from the highest levels of Government. Each representative has been designated by the head of his member agency or department.

Because of the size of the Committee, I have found that the best way to achieve committee objectives is through the creation of working groups. This allows committee member representatives to gravitate to those areas of committee work that are best suited to the representatives' particular talents or interests.

The committee has four working groups: Policy, Information Technology Initiatives, International Initiatives, and Symposium Management. I shall not elaborate on the responsibilities of each working group at this time, but I do want to give you some examples of the work that the committee has done. To do this, let me describe an initiative in each working group. The Policy working group played a significant role, in the review of the guidelines which I discussed earlier. I believe that our Policy working group had a major impact on the final content of the initial guidelines.

The Information Technology Initiatives working group had its major impact on the internal information resources management departments of the member agencies and departments by encouraging the heads of agencies to establish support structures for their own users with disabilities. Currently, fourteen of the twenty-four member agencies and departments have a formal support structure to deal with their internal computer accommodation technical issues.

The International Initiatives working group has been the slowest moving of the four working groups. It was first necessary for the U.S. Government to have its own policies in place before we could share them on an international level. I can tell you in all honesty that the guidelines have inspired interest as far away as Japan. I believe that once the guidelines are formalized, the International Initiatives working group will really take off.

Finally, we come to the Symposium Management working group. The Committee symposium has been a highlight of the committee. We started off small and had two hundred attendees the first year. Our last symposium had over eight hundred attendees. Last June we were a major participant in the Federal Computer Conference. As I mentioned earlier, the guidelines will be the focus of this year's symposium, so I expect to break last year's attendance record.

Over the years, the attendance at our symposium has become approximately a 50-50 mix between information resource managers and users with disabilities. It is gratifying to see federal managers take an active interest in disability issues. I believe that this year's symposium will continue in this direction in that many of our attendees will be federal managers and procurement personnel.

Over the years, the attendance at our symposium has become approximately a 50-50 mix between information resource managers and users with disabilities. It is gratifying to see federal managers take an active interest in disability issues. I believe that this year's symposium will continue in this direction in that many of our attendees will be federal managers and procurement personnel.

Now what about COCA? COCA started small. Until April 1988, COCA was managed by the Board's system manager, and staffed by one full-time analyst, and a college co-op student. But even with this small staff much was accomplished. COCA was the first information technology center devoted solely to disabled users. Here, federal employees could, if you will, play around with or experiment with, accommodation hardware and software; they could learn what other agencies or users have done; and they could obtain information about the state of the art in microcomputers. COCA has responded to over 300 requests for information, implemented over 30 hands-on solutions, and made presentations at numerous conferences. Today, COCA is recognized as an authority in the field of computer accommodation. Right now, GSA Information Resources Management Service is reviewing COCA with an eye to strengthening its role in the computer accommodation arena.

Finally, I should briefly mention two initiatives in which I am now personally involved as Chairman of the Interagency Committee. We are working with the Department of Education and the Government Printing Office to establish a procedure by which government agencies can obtain selected publications in large print, braille or recorded disk. Our objective is to make important Government publications accessible to the visually impaired. Also, since October, we have been working with the Office of Personnel Management to improve policies and procedures relating to the employment of personal assistants for disabled government employees. These initiatives emphasize the importance of creating a "realistic" environment for the employment of users with disabilities in the Government.

Mr. OWENS. Thank you very much.

Mr. Howard Stone.

STATEMENT OF MR. HOWARD STONE, DIRECTOR, SELF HELP FOR HARD OF HEARING

Mr. STONE. Thank you, Mr. Chairman.

I appreciate the opportunity of being with you this morning. My name is Howard Stone, but most people call me Rocky.

I am profoundly deaf, with a 110 decibel loss in both ears. But with the aid of assistive listening devices and good speech reading skills, I manage to function as a hard of hearing person in the hearing world.

I also have high constant shrill ringing of the ears, which is called tinnitus, and I'm blind in my right eye. But since public perceptions generally tend toward the obvious, clearly my problem is that I'm overweight. [Laughter.]

However, I'm the executive director of Self Help for Hard of Hearing People—SHHH. Literature is attached to my testimony today describing that organization.

I would like to demonstrate how assistive technology has contributed to changing life circumstances for me personally and by extension how it could change the lives of millions of other persons with disabilities.

At age 19, I became severely hearing impaired. Nevertheless, I was able to acquire a good education and experience a satisfactory career. At age 49, I became profoundly deaf, and a telephone was denied to me. In 1975, I retired at the age of 50.

As assistive listening devices developed from 1978 onward, I began to find improved ways of coping with my hearing loss and remaining in the mainstream of the hearing world. Induction audio loops, infrared systems, radio broadcast systems, FM and AM, became available to individual consumers in the 1980's. They gave me a new lease on life.

Although the method of sound delivery differs, all of these systems operate on the principle of improved speech to noise ratio. They take speech directly from its source into the listener's ear, thus eliminating most background noise.

My hearing aid, in contrast, only receives speech after it has traveled through the space separating you from me. The amplified hearing aid picks up whatever noise might be in that space.

The hearing impaired person often can hear the sound of speech, but cannot understand it. Assistive listening devices go beyond the hearing aid and permit persons like me to function in circumstances where previously we could not.

I am on several boards of directors. The Veterans Administration's Merit Review Panel, several research advisory boards and several consumer advisory boards. Most have over 25 members. I take this FM system with me, and I either place the transmitter in the center of the table or ask the speaker to hold it six inches from his or her mouth. I wear this receiver—I could not function without it.

I'm scheduled to travel more than 75,000 miles this year. When I stay at a hotel, I cannot hear the door knock, the telephone ring, or the fire alarm. Although the private sector is gradually responding to these needs, I cannot yet rely on them. I carry a visual alert system with me.

By simply plugging in the device, and attaching a transmitter to the door, I can be alerted by a flashing light that there is someone at the door, that the phone is ringing, or that there is a fire alarm.

Too often in the past I have been writing or reading in my room only to find out later that the building had been vacated in a fire or bomb threat while I serenely went about my business.

The visual alert system offers me safety and peace of mind, as well as the ability to answer the phone or the door. It can also be used to wake me up in the morning. Similar devices can be used in the home.

Although I cannot carry on a conversation on the phone, I can structure my calls in a way to successfully complete two-way communication of some messages. To enable me to do this, I carry a small device which slips over the earpiece of the phone and amplifies the voice of the speaker. Importantly, it also provides hearing aid compatibility to any telephone which is incompatible.

In the office, I frequently use a TDD (telecommunications device for the deaf). My job is telephone intensive. Unfortunately, not too many people have TDD's, with the result that I require an oral interpreter to carry on conversations in the other calls.

My church is equipped with an induction loop which is used in conjunction with hearing aids having an induction switch, commonly referred to as a T switch.

I watch television with closed captions and enjoy it. Prior to current levels of captioning, I did not enjoy television viewing. On occasion, I can also use an infrared listening system to facilitate the use of my auditory nerve while watching television.

Mr. Chairman, I have been describing usages of technology. But more importantly, I have been describing how a person who is disabled can continue to contribute to society.

Self Help for Hard of Hearing People would not be where it is today, changing thousands of lives for the better, if I did not know about and have access to this technology.

Demographics show us the future need to keep competent persons in the workforce longer, as our labor reservoir of young people shrinks. Yet older persons are losing their hearing faster than ever before.

Because of the lack of knowledge or access to assistive technology by themselves or by their employers, many are being forced out of their jobs or are relinquishing them voluntarily.

Mr. Chairman, the proposed legislation will develop awareness, permit access and bring all elements of society together in a focused effort to improve the contribution of persons with disabilities in the workforce, in their communities, to their families, and to themselves. It may even reduce the requirement for me and others like me to carry a suitcase full of gear wherever I go.

It is legislation truly worthy of our support.

One final comment: SHHH is developing a program called Access 2000. This is designed to make all places in the United States accessible for hearing impaired persons by the year 2000 which should be accessible to them.

Thank you and your subcommittee for inviting me to share my experience with you today.

[The prepared statement of Howard E. Stone, Sr., follows:]

STATEMENT OF HOWARD E. STONE, SR., REPRESENTING SELF HELP FOR HARD OF HEARING PEOPLE, INC. (SHHH)

Good morning Mr. Chairman, Subcommittee members, Ladies and Gentleman.

I appreciate the opportunity of being with you this morning. My name is Howard E. Stone. Most people call me "Rocky". I am profoundly deaf (a 110db loss in both ears), but with the aid of assistive listening devices and good speech reading skills, I manage to function as a hard of hearing person in the hearing world. I am the Executive Director of Self Help for Hard of Hearing People, Inc. (SHHH). I will attach literature describing our organization to my testimony.

Today, I want to demonstrate how assistive technology has contributed to changing life circumstances for me personally, and, by extension, how it could change the lives of millions of other persons with disabilities.

At age 19 I became severely hearing impaired. Nevertheless, I was able to acquire a good education and experience a satisfactory career. At age 49 I became profoundly deaf and the telephone was denied to me. In 1975 I retired at the age of 50.

As assistive learning devices (ALDs) developed (1978 and beyond) I began to find improved ways of coping with my hearing loss and of remaining in the mainstream of the hearing world. Induction (audio) loops, infrared systems and radio broadcast systems (FM and AM) became available to individual consumers in the 1980s. They gave me a new lease on life. Although the method of sound delivery differs, all of these systems operate on the principle of improved speech to noise ratio. They take speech directly from its source into the listener's ear, thus eliminating most background noise. My hearing aid, in contrast, only receives speech after it has travelled

through the space separating you from me, and the amplified hearing aid picks up whatever noise might be in that space. Hearing impaired persons often can hear the sound of speech but cannot understand it. ALDs go beyond the hearing aid and permit persons like me to function in circumstances where previously we could not.

I am on several Boards of Directors, the VA's Merit Review Panel, several Research Advisory Boards and several Consumer Advisory Boards. Most have over 25 members. I take this FM system with me and either place the transmitter in the center of the table or ask the speaker to hold it six inches from his or her mouth. I wear this receiver. I could not function without it.

I am scheduled to travel more than 75,000 miles this year. When I stay at a hotel I cannot hear the door knock, telephone ring, or the fire alarm. Although the private sector is gradually responding to these needs, I cannot yet rely on them. I carry a Visual Alert System with me. By simply plugging in the device and attaching a transmitter to the dor, I can be alerted by a flashing light to someone at the door, a ringing phone, or a fire alarm. Too often in the past I have been writing or reading in my room only to find out later that the building had been vacated in a fire or bomb threat while I serenely went about my business. The Visual Alert System offers me safety and peace of mind, as well as the ability to answer the phone or the door. It can also be used to wake me up in the morning. Similar devices can be used in the home.

Although I cannot carry on a conversation on the phone, I can structure my calls in a way to successfully complete two way communication of some messages. To enable me to do this I carry a small device which slips over the ear piece of the phone and amplifies the voice of the speaker. It also provides hearing aid compatibility to any phone which is incompatible.

In the office I frequently use a TDD (Telecommunication Device for the Deaf).

My church is equipped with an induction loop which is used in conjunction with hearing aids having an induction switch commonly referred to as a "T" switch.

I watch television with closed captions and enjoy it. Prior to current levels of captioning, I did not enjoy television viewing.

Mr. Chairman, I have been describing usage of technology, but more importantly, I have been describing how a person who is disabled can continue to contribute to society. SHHH would not be where it is today—helping change thousands of lives for the better, if I did not know about and have access to this technology. Demographics show us the future need to keep competent persons in the work force longer, as our labor reservoir of young persons shrinks. Yet older persons are losing their hearing faster than ever before. Because of lack of knowledge or access to assistive technology, by themselves or by their employers, many are being forced out of their jobs or are relinquishing them voluntarily.

Mr. Chairman, the proposed legislation will develop awareness, permit access and bring all elements of society together in a focused effort to improve the contribution of persons with disabilities to the work force, in their communities, to their families and to themselves. It may even reduce the requirement for me and for others like me, to carry a suitcase full of gear wherever I go. It is legislation truly worthy of our unstinting support.

Thank you and your committee for inviting me to share my experience with you today.

Items demonstrated or shown: FM listening system; VAS—Visual Alert System; Amplifier—compatibility device TDD; Induction loop—picture; Closed captioning—picture.

Attachments: SHHH fact sheet, brochure, and journal.

SHHH Fact Sheet

More than 25,000 persons have joined SHHH since 1980.

220 chapters and groups are meeting in 43 States, with more continuously forming.

Members in 17 countries including two National Offices (USA and Australia) and an affiliation in Canada.

10 full-time paid staff with a full-time volunteer Executive Director. 3 part-time paid staff.

16 States where OPERATION SHHH is being implemented. (Anti-Noise/Hearing Conservation Program for Children).

218 SHHH volunteers working in 135 nursing homes in 42 States and Canada.

Shhh, A Journal About Hearing Loss, published bi-monthly in 43,000 copies and over 200,000 readers.

Large print edition of Shhh in process. (Funding required)

Extensive publications list from which to learn about many aspects of hearing loss, its complications and possible accommodations.

Two internatioinal conventions held with two more in process (1988, Rochester, N.Y.—1989, Bethesda, Maryland—Tenth Anniversary celebration)

Training programs, workshops and conferences—an ongoing experience.

SHHH travel tours geared for hard of hearing people.

Working closely with major organizations involved in the problem of hearing loss.

Assistive Listening Devices Demonstration Center.

An inventory of places with assistive listening systems (PALS) in the U.S. Some 20,000 PALS are located in places of worship, theaters, community centers, libraries, etc. and allow hard of hearing people to participate in events not otherwise accessible to them. Upon request, hard of hearing travelers will be provided information about PALS at places in t'.eir itinerary.

Distinguished Service Award for 1987 from American Speech-Language-Hearing Association.

Mr. OWENS. Thank you very much, Mr. Stone.

I want to thank all of the witnesses. Your written testimony, of course, could tell us a great deal, but your presence here today has communicated so much more.

I have one basic question that I want to ask. I apologize for focusing in just on costs, but that's what the Federal Government probably could help with most—costs.

Getting the technology and being able to pay for it is not the only answer, as several of you have pointed out, but certainly it is the beginning to the answer to a lot of those problems.

Mr. Stone, your suitcase full of gear, that very impressive set of devices that you have—what does all that cost?

Mr. STONE. Well, all of these costs vary greatly.

An FM system can cost from $400 to $800. This particular system cost $800.

Infrared systems vary depending upon the individual and the size of the room, for large room listening. An individual infrared set can cost anywhere from $125 to $300.

Audio loop systems are by far the least expensive. For $150 or $120 you can loop your television or your office in such a way that your hearing aid can be the most useful factor in communicating in a different way. That's an inductive mode rather than a microphonic mode.

TDD's, as the young lady before me mentioned, range anywhere from $150 to $1,000. This one, as you can see, has a tape on it, as well as the visual readout. That cost about $350.

So, there are tremendous ranges, and by the legislation that you are designing to coordinate not only means of access but to develop and weed out duplication that it would in all probability lead to—I think the prices will come down significantly.

When people know they exist, and know how to find them, and when they have means of purchasing them, then the law of supply and demand will come into play and bring those prices down much more.

Mr. OWENS. Have you stayed in a hotel which had some of those devices available, so that people don't have to carry them around with them?

Mr. STONE. Yes.

What we're trying to do is to persuade industry and the hotels to purchase the visual alert system so that the individual does not have to bring it with them, or buy it.

The Holiday Inn Corporation has committed themselves to all their corporate hotels having this system. You simply ask for it at the desk. Hampton Inns also—every one has one of these systems.

Gradually, other corporations are beginning to catch on. But the big problem in our country is that it's so large. Dissemination of information is a major problem for organizations such as ours.

If we had the help and support of the Government in developing awareness of what systems were available, where, and for how much, it would make a great deal of difference to many of us.

Mr. OWENS. Thank you.

Judge Suchanek, you said your unit was the first automated with full accessibility.

Can you tell us a little bit about the cost there?

Judge SUCHANEK. Well, in 1980, we automated the entire office. In that process, we also brought in automation for myself, and the major component in that system was a Braille printer. This was purchased in 1981. At that time, it was considered to be a high-speed Braille printer, and it cost about $15,000. We wore that printer out in about five years and then went to another printer that prints Braille on both sides of the page.

With a discount, that cost us somewhere around $32,000.

Mr. OWENS. That's $32,000?

Judge SUCHANEK. Yes.

And we print for myself, as well as for others, on the average of between 200 and 300 pages of Braille a day.

Mr. OWENS. Thank you.

Ms. Bibum, you mentioned a hearing device the cost of which was between $150 and $1,000. How is there such a disparity in cost? What do you get for $150 versus $1,000? Can you get an adequate one for $150; what is the difference that you're purchasing?

Ms. BIBUM. It depends on the capacity of the machine itself. For example, the cheaper machine will be smaller. It's called a Mini-Com. I have that one at my home. There's no paper or tape, as this one over here has a paper tape. It has paper in it for the printer, and this one here costs about $300 or $350. I'm not sure exactly.

The cheaper one doesn't have the paper. The $1,000 one is a more advanced computer type. So it depends on the capacity. Some of them have memories. Some have an answering machine combined within the TTY. That's a more sophisticated machine.

The one that I have at home is very satisfactory. I wish that it had paper in it, because I have to run and get a piece of paper to take down messages, but it's also portable as well.

Mr. OWENS. Thank you.

I think Ms. Adams mentioned a machine that's before her. I think that one cost $5,500, and there's only one manufacturer. Am I correct? There's only one manufacturer in the world that makes it?

Ms. ADAMS. I don't know about the world.

Mr. OWENS. In this country, there's only one manufacturer?

Ms. ADAMS. Yes.

Mr. OWENS. There's another device?

Ms. ADAMS. Yes.

Mr. OWENS. A device that goes with that computer that would cost $3,500?

Ms. ADAMS. Well, it has different options. You have one called Versa-Braille, and that costs around $6,000, but it's already a computer, and it can connect to other computers for more power.

They also have the option of—we also have other options called the BDP, meaning Braille space Display Program—I think that's the P. That's only Braille output that's connected to an IBM compatible or maybe an Apple computer.

Really, we have many options for which the prices may increase or decrease. They should decrease if we have the increased competition. Because we have only limited manufacturers, like for the Braille printer, the cost is extremely high.

Mr. OWENS. Thank you very much.

Ms. ADAMS. You're welcome.

Mr. OWENS. I yield to Mr. Bartlett.

Mr. BARTLETT. Mr. Chairman, this excellent panel has provided us some very good information.

Let me ask each of the panelists a broad question. This is as to availability of technology.

The technology that you've shown us today, as well as that in general—how would you characterize the availability of knowledge about technology for particular disabilities? Were you able to—for the devices that you use—find out about the technology in easy ways? Are disabled people in general able to find out about what is available? And what are the sources of that knowledge or information about available technology?

Mr. Stone, we should start with you, because you're in the business, at least in part, of providing knowledge about available technology.

How would you assess this?

Mr. STONE. Well, I'll tell you a brief story, Mr. Bartlett.

When I decided to found Self Help for Hard of Hearing People, the reason was that I thought I knew all about deafness since I'd had it for 30 years.

The first thing I discovered was that I don't know anything about that either. It took me two years of research and study and talking to people to begin to feel comfortable with the problem and to locate the resources concerning it.

Most of the assistive listening systems that I've described have only come on the market since the 1980's. The audio loop is an old device of European usage, but very limited in American usage.

FM systems were not authorized by the FCC for individual use until 1982. They were previously auditory trainers in school settings.

Infrared was a German invention that came in the late 1970's and into the United States in the 1980's.

I had to be interested enough in an organizational sense to seek this information out. The average individual does not have access to that.

Because of our organization, we have 200,000 readers of our journal now, and those people do have access to the latest technology because we report on it. But ours is the only national organization for hard of hearing people who number over 11 million in the coun-

try. This is opposed to deaf organizations who have well established channels of dissemination over the years.

Even there, though, the access is limited. When California started to give away TDD's, they thought they were going to give away 250,000. It took them five years to give away 15,000 TDD's in the State of California. Part of the reason for that is the unfamiliarity and lack of knowledge of technology and lack of knowing how to get it.

Even in that limited circumstance, the problem was tremendous.

Mr. BARTLETT. Let me make sure that I understand. You're saying that the State of California set out to give away 200,000 TDD's?

Mr. STONE. That's right.

When the system was first set up, the projection for people needing TDD's in the State of California was 250,000. After five years, they had only given away 15,000 TDD's.

Mr. BARTLETT. So today, if a person is hearing impaired, and wants to obtain a wide array of assistive devices to determine what is available, where does that person go? Other than the ads in your magazine?

Mr. STONE. Well, we are helping to work with the professionals.

In the case of audiologists, whom most people will see, or hearing aid dealers—I won't say most, since only 3 million out of a possible 13 million people who could use amplification actually use it. When they go to these people, you hope that the hearing aid person or the audiologist knows about all these devices.

Up until just recently, they did not. In many cases, the consumers were involved in educating the professionals about the existence of these devices.

We were also involved with putting configurations of simple communications gear from Radio Shack together to provide ourselves with a means of communications because of our hearing disabilities. But that's tricky. That can cause a lot of problems, since there are standards involved, and we don't always know what we're doing in terms of something that is complicated.

We do need professional assistance.

Mr. BARTLETT. Well, Mr. Stone, let me personalize it if I could, and perhaps that's not unfair.

You're using a device here made by Telex, an FM wireless microphone, which you described. Is this device useful for—what percentage of hearing impaired persons is this device useful for?

Mr. STONE. Well, if you are mild to all the way up the range to severe, you wouldn't need it.

By the time that you get to severe and profound, the 4 million to 5 million people who have severe hearing impairment could benefit from that device. Some of the 2 million people who are deaf could benefit from it.

I am audiologically deaf, but I have, like many deaf people, a little residual hearing. So this device, because it excludes background noise, reduces the fatigue that I have in reading your lips from this distance. It permits me to understand your speech better because the noise goes from your voice into my ear. My discrimination is better.

All of these things contribute to a better capability for me to function.

Now, I would say that a small percentage of deaf people could benefit from them, and about 90 percent of the severely hearing impaired, which is about 4 million to 5 million people. We don't have accurate statistics on that. They could benefit from this device.

Mr. BARTLETT. And of the 4 million who could benefit from this device, how many have it?

Mr. STONE. Oh, I would say less than 200,000. Far less.

Mr. BARTLETT. And what's the chief impediment or barrier to those 4 million people who could benefit from it from getting it?

Mr. STONE. Lack of knowledge is the primary one, and cost is secondary. But it's primarily lack of knowledge.

In the case of the hearing impaired person, there's also the major problem of denial and stigma. This is particularly with men who do not want to be associated with any visible evidence of hearing impairment.

I would say that stigma is second after lack of knowledge. Even if they know about it, stigma prevents them from doing anything about it.

The third thing is the price.

Mr. BARTLETT. Okay.

Judge, I'm sorry, I've forgotten how to pronounce your name.

Judge SUCHANEK. Suchanek.

Mr. BARTLETT. Suchanek. Judge Suchanek, when you helped to develop accessibility for the GSA, how did you find the state-of-the-art as far as determining what was available so that GSA could begin to disseminate it?

Judge SUCHANEK. In terms of my personal experience, Congressman, in 1981, I simply started calling around and checking with friends of mine who were members of handicap groups. That's how I found out about the Braille printer that we eventually purchased.

I might add that if you were to refer to the top of page six of my paper, I state there that in 1983 and 1984 really there were no policies in Government at all relating to the area of technology. I state there, and I'll read it to you: "This is not to say that computer accommodation did not exist. There were several agencies that were involved in computer accommodation at that time. But this was only on a case-by-case basis. There were no information exchanges, support mechanisms or procedures. In most cases, it was a continual rediscovering of the wheel."

That had an awful lot to do with getting the interagency committee going. We discuss later on in this paper, Congressman, how the interagency committee has impacted several of the agencies and departments in getting them to set up and organize internal mechanisms for computer support of the disabled.

Mr. BARTLETT. Well, Judge, in setting up the interagency, what was available? How did the interagency find out what devices were available out in the world of the companies that produce these devices?

Judge SUCHANEK. It was a matter of contacting an awful lot of organizations. There's really no central source for information. We

simply talked to a lot of people, did a lot of reading, contacted a lot of organizations, and worked it that way in terms of gathering information.

In fact, the interagency committee set up in conjunction with GSA and the organization, the acronym of which is COCA—if I recall correctly, Congressman Bartlett, you were at the opening of COCA.

COCA started small. Actually it was run basically by two people, one of whom was my own computer person from the Board of Contract Appeals.

COCA was the first information technology center devoted solely to disabled users in the Federal Government. Here Federal employees could, if you will, play around with or experiment with accommodation hardware and software. They could learn what other agencies or users had done. They could obtain information about the state of the art in microcomputers.

I then went on to explain that COCA has responded to over 300 requests for information, implemented over 30 hands-on solutions, and made presentations at numerous conferences and so on.

I emphasize, although this sounds great, that it's really only a start. It's—we've gotten tremendous support from managers throughout the various agencies of the Federal Government including GSA and we hope that we receive that continued support, not only from them but also from you.

Mr. BARTLETT. Okay.

Thank you.

Ms. Bibum, how would you characterize the availability of knowledge about what devices are available? Both for hearing impaired and for other disabilities, from what you know?

Ms. BIBUM. All right.

My organization, Deafpride, does information referrals. So in a way it's our business to know what's available out there.

As a deaf person myself, my husband and son are both deaf as well. So I come from a deaf family. We know what's available in our community.

For example, there are two stores that are owned by deaf businesspeople who sell TTY's and other technological equipment related to deaf people.

Now, one serious problem is that 10 percent of deaf children have deaf parents. This means that they grow up most of the time knowing what they need to survive.

The other 90 percent of deaf children have hearing parents, and many times those parents are having their first experience with deafness by having a deaf child. The parents don't know what to do at all. Many times they don't know what resources are available.

If they contact some place like Deafpride or Self Help for the Hard of Hearing, that's great. But many parents are not familiar with such organizations.

For example, my deaf son goes to Kendall School on the campus of Gallaudet University. He knows what's available. He knows that if he wants to call me at work and let me know when basketball practice is, he knows how to access the TTY to call me.

He has a friend who's one year older who had never even seen a TTY. This friend came into our house about 2 or 3 months ago and

had never seen a TTY. He had never seen a TV decoder or a flashing doorbell light. That youngster is 13 years old and has no access to information. And his parents have no access to information.

So it's not always a question of low income. With that particular family, yes, they were a low income family. But still, in the first place, they had no idea that their son could get such technological aids.

Yes, the school will provide a hearing aid, but that's it. That's all that they provide, and there is more technology there for deaf young people than just hearing aids.

Mr. BARTLETT. Thank you.

Ms. Adams, how did you discover or how do you discover technology that is available? What are your sources?

Ms. ADAMS. For myself, I am in contact with the deaf-blind community. I work in an office called the American Association of Deaf Blind People. We have information there.

We know what's happening. But I can't say that for every deaf-blind person. It's so diverse, because sometimes a deaf-blind person is born prelingually deaf-blind, and they have very different needs from a person who becomes deaf-blind perhaps by accident later in life. Perhaps that person was born deaf and loses their vision later.

It depends on where they go to school, it depends on what they know about some devices. Some people who are deaf may not know about blindness, and some people who are blind might not know about deafness. There's such a diversity, and we can't be specifically—what is the percentage of the deaf-blind population? We don't know exactly.

Some people who are born prelingually deaf and then later become blind—I'm one example of that incidence. So I knew about TTY's, but I didn't know about the Tele-Braille system. So it really depends on how the people—what their experiences are and how they can access these services.

There's such a diversity.

Mr. BARTLETT. Thank you.

Mr. OWENS. Thank you.

Mr. JEFFORDS. We've had excellent testimony, in particular about how more people need to learn about devices that are available.

Let me ask the question the other way around.

It would seem to me that we have two extremes with respect to trying to develop equipment. One is where you have a very individualized system necessary which only a few people in the country utilize. The other extreme is where you have a rather general disability for which a large number of people could use a certain technology that's available.

Now, my question is, looking at it from the other way around, with respect to trying to get the number of devices from the second group used to reduce the cost—obviously, if you build the demand up through information to the individuals who need them, that's one way.

But what about the other way? Do we have any system that lets potential manufacturers know of the available technology and the large numbers of people who may need to use it, to invite people into the manufacturing in order to disseminate and reduce the cost of technology that's available?

Mr. Stone?

Mr. STONE. We have spent quite a bit of time, both with existing manufacturers and people who would like to get into the manufacturing business of devices, talking to them about marketing problems and whether or not the product would fly in terms of price and usability.

I think that one of the biggest things that we're missing here, and we're not going to get into it very deeply, but let me just say that most of the people who are hearing impaired—of that 21 million people, about 18 to 19 million are people who were hearing people who have lost their hearing.

The result is that they're still in the culture of the hearing world, and their methods of communication and reception of information are from the hearing world. That's not where the information is, except for hearing aids, perhaps.

The information regarding devices is generally in existing channels of deaf organizations which have long been engaged in the education of their constituents.

In the case of the hard of hearing person, the hearing person who has lost hearing—we're just organized for the first time in the last 10 years. Availability of this kind of information to that large community is very scarce. Until we raise the level of awareness of the whole hearing community to start talking about these things in normal terms, most of the hearing people are not going to find out about it.

They don't gravitate toward the publications of deaf people. They're still afraid of becoming completely deaf. That's a tremendous concern, and they still have the prejudices of the hearing people toward deaf people, which ultimately they're going to have to confront and give up. If they want the kind of consideration that they expect from you, they're going to have to give that same consideration to our deaf brothers and sisters.

It's a real attitudinal problem that's complicated. Manufacturers, generally speaking, are aware of the numbers, and many of them have gone broke because they see this enormous market out there and it isn't really what the numbers reflect. Many of the attitudinal stigmas prevent people from buying the devices even after they know about them.

I think that after thinking about it a few minutes while the others were talking, I would stick to that order of progression. It's lack of information, it's stigma, and then it's cost.

Mr. JEFFORDS. Thank you.

Would anyone else like to comment?

Judge SUCHANEK. I make my comment realizing that information exchange is a tremendous problem, not only for the disabled but also from the perspective of industry.

The interagency committee began or set up a working group called Symposium Management. Three years ago, we began putting on a symposium each year in conjunction with the National Computer Conference, to bring together not only disabled people but people from industry and managers and employers in Government as well to provide this information exchange and to show managers, employers and the disabled what is available and what can be done.

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Last year, that conference was highly successful. It was something that was not easy for us to put on, since we did it through volunteers. We were not financed. Last year we had 800 attendees.

Mr. JEFFORDS. Thank you.

Ms. BIBUM. May I say that I think it's really a cycle, a vicious cycle. The manufacturers may go out of business, or when the production volume is low the costs increase. Many of us deaf adults know what is out there. We know about the TTY's, the alarms, the flashing lights, and so forth. But many people are not able to afford this equipment.

How we resolve that, I don't know. Perhaps with some kind of Government funding, perhaps through RSA. But RSA still doesn't provide sufficient equipment to deaf adults or to young deaf people who are looking for jobs.

One barrier that many deaf people have is this—they look for jobs, and they may keep the job, but communication is a problem.

Suppose they get a job, and then perhaps become ill and can't call work to let them know that they're ill and not able to come to work? Then they're fired. So perhaps the Government can allocate money.

In our community, we know that we have this equipment available, but we're not able to afford it.

Mr. JEFFORDS. Thank you.

Ms. ADAMS. Yes, and I'd like to say that we have this various technology available.

Time doesn't allow me to explain so much about how deaf-blind people can be independent. We have this type of technology available, but we're not always able to access it to our full potential to be independent.

This Tele-Braille equipment really has opened up so much for me. When I first got this equipment, it was terrific. It opened up a whole new world for me. I was cut off from so much.

I hope that the Federal Government can do something to help us.

I don't know of any programs that are able to give money to deaf-blind people. I do know there are some States that do provide free TDD's, like California, and the Tele-Braille's. I don't know about others.

Thank you for hearing my testimony.

Mr. JEFFORDS. Thank you.

Mr. Stone?

Mr. STONE. I'd like to add one word of caution.

I think that it's very clear from what everyone is saying that we do need financial help on these devices. Some of them are out of sight.

In terms of the people that we're dealing with, however, I would issue one word of caution.

Provision, for example, of an assistive listening device or a hearing aid free may not be the answer unless you consider the motivation for usage.

If in any legislation you're proposing, you fail to consider the motivation of the user, it's not going to help too much to give that person a device, if they're not motivated to use it.

That has been proven in a number of different countries and in our own experience in the United States.

Clearly, we have to match up some financial assistance with motivation to make that a very usable kind of help.

Mr. JEFFORDS. Thank you.

Thank you, Mr. Chairman.

Mr. OWENS. Again, we thank all of the panelists. We are going to proceed on the basis of what you have communicated to us this morning, and in your written testimony.

But what you have communicated by your presence is invaluable, and I thank you again for coming.

Our next panel consists of Ms. Alexandra Enders, Project Manager, Rehabilitation Engineering Delivery Program, Electronics Industry Foundation; Dr. Barbara Boardman, Senior Analyst, Health Program, Office of Technology Assessment; and, with your indulgence, because of a time problem, Mr. Jerry Weisman, from Rehabilitation Technology Services in Burlington, Vermont.

We'll take Mr. Weisman first.

Is there anyone in the audience who would need an interpreter? We can continue this if there is a need for it. Is there anybody who still needs one?

All right, thank you.

We will proceed.

I'll let Mr. Jeffords introduce Mr. Weisman.

Mr. JEFFORDS. Thank you very much, Mr. Chairman.

It's with a great deal of pleasure that I introduce to you Mr. Gerald Weisman.

He has a Master's degree in mechanical engineering, and is one of the project directors on the staff of the University of Vermont's Rehabilitation Center for Lower Back Pain, and in addition is with Rehabilitation Technology Services, a private company which designs and makes individualized technological and mechanical accommodations for individuals with disabilities.

Such accommodations have been made by Mr. Weisman for children and adults to increase their ability to participate in their homes, at school, and at work.

We all like to think that we impact positively on the lives of others, and Jerry has demonstrated how to do it for the last 12 years.

We deeply appreciate your presence. Thank you, Jerry.

Mr. OWENS. Mr. Weisman, you may proceed.

STATEMENT OF MR. JERRY WEISMAN, REHABILITATION TECHNOLOGY SERVICES, BURLINGTON, VERMONT

Mr. WEISMAN. Thank you.

Mr. OWENS. Can you pull the mike closer?

Mr. WEISMAN. It's an honor to be here today.

As a rehab engineer for the last 12 years, I've been involved with and responsible for the delivery of rehab technology services to persons of all ages with all types of disabilities.

It's easiest for me to show you what types of things are involved by bringing slides with me.

Having grown up in Brooklyn, and lived on Vernon Avenue for a while, I moved to Vermont. I've brought along a slide that's hard to see. There are some misconceptions about the size of Vermont

since we only have one Representative to Congress. But you can see from this——

[Laughter.]

Mr. WEISMAN. The importance of the work at our Rehab Center can be seen from our next two slides. Some 75 million Americans are affected by chronic lower back pain. The cost of this lower back pain is estimated to be about $56 billion a year.

We hope that the work that we're doing at the Rehab Engineering Center will have an impact on these numbers. What I'd like to do, because I can't bring all the clients that I've worked with, is to bring some slides and show you some of the things that we've done.

When I first met Danny, he was two years old and had cerebral palsy. He couldn't get around by himself. We wanted him to be able to get around by himself so he could get into trouble the way all two-year-old toddlers do. We bought a cart from Sears for about $125 and modified it for about $250, and he could get around all by himself.

Sean was 12 when he first came to us, positioned already in a chair, but never having been able to get from one place to another by himself. We modified his chair and developed a wheelchair control system for about $1,000 that allowed him to get from one place to another. Watching his father watch him was like watching a father watch his son drive a car for the first time.

Maura was in high school when we first met her, with cerebral palsy using an Apple computer to do all her homework. She uses two switches allowing her to use Morse code through a commercially available product known as a Firmware card, to access the computer. She can type about as fast as anybody who uses the hunt-and-peck method.

Bob was a quadriplegic who was a photographer before becoming injured with a spinal cord injury. Rather than spending $600 or $700 on a fancy new electronic camera that he may have been able to use, we just modified his old one for about $100. He could then still take pictures and enjoy photography.

I apologize for the darkness of this slide. It shows a three-wheeled cart that we made for Rick. Rick was 17 years old when we met him, and lived in Boston. He had a family that was very outdoorsy. They liked to be outside but couldn't find a wheelchair that would hold up outside. We made him this three-wheeled cart for about $150.

His father started to push him in road races, and they eventually ran in the Boston Marathon. They've been running the Boston Marathon for the last six or seven years, and have since entered Iron Man competitions.

This was Joe, who was a barber for about 30 years and then lost a leg to an amputation. He couldn't stand up all day and still provide all the services that he did. For a couple of hundred dollars, we got a chair so that he could still provide all his services and keep his shop open.

Daisy was a person who lived in upstate Vermont who wanted to be able to sew, but because of her double above-knee amputation, she had no feet to operate a foot pedal on an industrial sewing machine. It was replaced with a pneumatic cylinder and a head control was developed, and she could sew, becoming one of the fastest operators in the plant, using that head control.

Horse was a lineman for a cable television company who fell off a pole, broke his back and became a paraplegic. He had worked for this company for 7 years and was a good employee, and the employer wanted to keep him.

He demonstrated his abilities and what he could do, and demonstrated that he could get up into the bucket of a truck with his long leg braces. Once he was in that bucket, he was the same as anybody else, and could go back to work with about $3,000 of modifications to his truck. Most of these were things like grab bars on the outside of the truck that he could hold onto as he walked around.

There were benches added to the inside so he could have mobility inside the truck. In Vermont, it's important to have heaters in the bucket, if you're working on top of the pole in winter, and hand controls to drive them.

We have a saying in Vermont that you can't get there from here, and sometimes you need snowshoes to get there. We have a company in Vermont which makes snowshoes, and they use a lot of home work people, to make these snowshoes at home.

David used this old rig that held a snowshoe rigidly, but because of his limited mobility and hand dexterity, he easily became fatigued and couldn't work more than half a day. We made up a rig that allowed him to rotate the snowshoe while he worked on it. In that way, he could sit on a stool in one place and be productive all day long.

On a personal level, these examples of technology are as significant as landing a man on the moon. But at the same time, they're not pie in the sky solutions. We're not spending a lot of money on these things.

The prospect of legislation enabling the development of rehab technology services for people with disabilities of all ages is very exciting, and one that's most welcomed by the Vermont Rehab Engineering Center and Rehab Technology Services.

In considering such legislation, at least six issues should be addressed, in order to ensure that quality services are provided in an efficient and cost-effective manner by competent people.

Acquiring appropriate technology has greater implications than simply acquiring the funds to purchase commercially available equipment. Services that go beyond traditional medical and rehab models include specific technology expertise that must be provided to ensure the appropriateness of the technology.

None of the examples provided above would have been possible if we were dependent solely on the commercially available products. Reinventing the wheel is a common activity in the present dissident network of service providers. A network should be developed to share the engineering so that it does not have to be duplicated.

Thirdly, programs to increase awareness are extremely important in the effort to provide technology assistance. There is an obvious need for the training of rehabilitation engineers. Legislation to establish rehabilitation technology service programs will greatly increase the needs for technologists, especially rehab engineers. The current shortage of engineers in the service sector will become extremely acute, unless a concerted effort is made to establish training programs to produce these professionals.

Fourth, legislation to establish technology service programs must address the need to fill the gaps of present funding for adaptive equipment delivery mechanisms, and not duplicate it.

Five, at the present time there is no way to identify a qualified rehab technology service provider. The expansion of service delivery programs with the concomitant infusion of monies makes the identification of these qualified personnel most important.

Lastly, the lack of liability insurance for many technology providers presents some major problems, not only to providers themselves but to their clients and to society.

The single biggest problem with the lack of liability coverage for assistive technology providers is the lack of protection afforded the consumers of these services.

The benefits of technology to the lives of persons with disabilities have been clear for some time. The time is right to enable the development of comprehensive rehab technology service delivery models through legislation.

We at the Vermont Rehab Engineering Center for Lower Back Pain and Rehab Technology Services support this legislation, and are committed to doing anything we can to help bring these concepts to fruition.

Thank you very much.

[The prepared statement of Gerald Weisman follows:]

STATEMENT OF GERALD WEISMAN, M.S.M.E., REHABILITATION TECHNOLOGY SERVICES, VERMONT REHABILITATION ENGINEERING CENTER

It is an honor to be given the opportunity to testify before the Subcommittee on Select Education and Labor pertaining to technology related needs and assistance for persons with disabilities.

As a rehabilitation engineer for the last 12 years I have been involved in, and responsible for the delivery of rehabilitation technology services to persons of all ages and with many types of disabilities. At the present time, I am one of the Project Directors for the Vermont Rehabilitation Engineering Center (REC) for Low Back and the Director of Rehabilitation Engineering for Rehabilitation Technology Services, an affiliate of the Vermont REC and the University of Vermont.

The Vermont REC is one of the NIDDR funded rehabilitation engineering centers and the only one whose focus is low back pain. Vermont has recently been awarded a second 5 year grant to continue the work begun 5 years ago. The mission of the Vermont REC for Low Back Pain is the improvement of our understanding of the diagnosis and successful rehabilitation of people with low back pain (LBP), with the ultimate goal of improving quality of life of these individuals and reducing the socioeconomic costs of LBP through a comprehensive and integrated program of multidisciplinary research and information dissemination activities.

The successful rehabilitation of those who LBP is of critical medical and socioeconomic importance. LBP, the most common musculoskeletal disorder, is also the single greatest source of compensation payments, and the second most common cause of work loss. The number of Americans affected by chronic backaches is estimated to be 75 Million. Prevalence rates are increasing as is the attendant disability. According to the National Center for Health Statistics, impairments of the back or spine (excluding spinal cord injury) are the third leading cause of impairments in the U.S., affecting 11,700,000 persons (5.2% of the population), second only to hearing and sight impairments. However, disabling impairments of the back or spine are the leading cause of disability in the U.S., affecting 5,300,000 (2.3%) of the population. Between 1971 and 1981, the numbers of people with back or spine disabilities increased by 168%, while the population of the United States increased by 12.5%. Seventy-nine percent of these persons are in the age group 17-64, the peak of productive, wage-earning years. Corporate expenses alone, involving the treatment, lost production and retraining due to LBP have been reported to exceed $56 Billion in 1987.

In the past four years, the Vermont REC has undertaken several studies that have incorporated the design, development and evaluation of new technology. These

include measurement tools (3-axis goniometer, hand-held force meter, isokinetic strength tester), surgical instrumentation (Vermont Spinal Fixator), a compliance meter for monitoring brace and corset wear, and various types of experimental apparatus. Additionally, a computerized patient questionnaire has been developed to make it possible to gather information on a wide range of factors presumed to influence outcome of low back episodes and thus lead to the prediction of whether or not a person will become disabled due to LBP. Current projects will continue to; identify risk factors for back injury, pain and disability; develop measurement methods for assessing strength, rehabilitation potential and effectiveness; evaluate various treatment including orthotics, movement, manipulation and exercise; develop methods for assessing both worker and workplace to enhance the development of worksite design and modifications to reduce or eliminate low back injury and to facilitate early return to work for those injured; expand as a nationally-recognized repository of information on the diagnosis, treatment and prevention of LBP.

Rehabilitation Technology Services (RTS) is a primary mechanism through which technological advances developed at the Vermont REC are applied to meet the needs of people with disabilities. RTS's primary purpose is to improve the quality of life of such individuals through the efficient and cost effective delivery of rehabilitation technology services. Engineering consultations are provided to identify problems and seek appropriate solutions. Resources are maintained for the modification and fabrication of equipment. RTS offers consulting services and technical assistance in the areas of worksite modifications, mobility, seating and positioning, communication, activities of daily living needs, educational needs and architectual accessibility. These services have been provided to persons of all ages with many types of disabilities.

RTS is the primary provider of rehabilitation technology services in Vermont. Services are provided through contracts and fee-for-service through such agencies as the state Vocational Rehabilitation agency, Handicapped Children's Services, special education departments, acute rehab facilities and public and private rehabilitation and business organizations.

Having provided rehabilitation technology services in the northern New England area for the last twelve years I have been witness to the increasing awareness and interest of persons with disabilities and professionals in the benefits of technology. A few examples of rehabilitation technology services will illustrate the process as well as the benefits.

Dan was two years old when his parents thought it would be a good idea for him to be able to get around by himself. Because of cerebral palsy Dan was unable to walk or even move around independently. He therefore couldn't explore his environment and "get into trouble" as all toddlers are apt to do. A toy cart was purchased from Sears for $125 and modified at a cost of $250 to enable Dan to operate it independently. Dan has acquired the ability to move through his environment independently. Most of the benefits of this mobility will manifest themselves later in Dan's life as near normal psycho-social development.

Sean was 12 years old before he was given the opportunity to move from one place to another without assistance. A custom designed wheelchair control system enabled Sean to retain the benefits of his existing postural wheelchair. The $1,000 spent by the school system to modify Sean's chair was soon seen to be cost effective as Sean began to work in the school cafeteria sweeping the floor with the broom attached to his powered chair.

Marla is a very intelligent young woman. Functional limitations due to cerebral palsy prevented her doing much of her homework in high school in a traditional way. A modification known as a "firmware card" enabled Marla to access an Apple computer through two switches. The switches represent the dots and dashes of morse code. By properly positioning the switches, Marla has independent access to the computer. Using morse code, she can type almost as fast as someone using the "hunt and peck" method of typing. She is now in college and on her way to a bachelor's degree.

A spinal cord injury at the C-7 level left Bob a quadriplegic with no use of his fingers. An avid photographer, Bob hoped a way could be found to allow him to continue to take pictures. After looking at new "electronic" cameras that cost upwards of $650 and were too expensive for Bob, a way was found to modify his own camera for about $150 to enable him to access the various controls. A commercially available support was purchased and mounted to his wheelchair. Bob continues to receive enjoyment and satisfaction from his hobby.

Rick belongs to a very special family that enjoys the outdoors. In spite of his cerebral palsy he participates fully in family outings. When he was 17 the need for a wheelchair that could be pushed but not fall apart when going over rough terrain

was identified. Because there was nothing commercially available at the time, a custom made three-wheeled cart was designed and fabricated for about $350. His father was soon pushing Rick while he jogged. The year after the cart was fabricated, Rick and his father ran, unofficially, in the Boston marathon. It was not long before they were given permission to "officially" in the marathon as a handicapped entrant. Marathons not being enough, Rick and his father were soon competing in and completing Ironman contests.

Joe had been a barber most of his life and had his own barber shop for about 30 years. After having a below knee amputation, Joe found that he could not tolerate a whole day standing up and cutting hair. He acquired a seat, for about $200, that revolved around the base of the barber chair. The seat allows him to sit while cutting hair, thus taking the load off of his amputated leg. He is now able to cut his customer's hair all day and keep his shop open.

Daisy wanted desperately to work. Living in northern Vermont, the opportunities for a person who had bilateral above knee amputations were limited. The largest employer in town was a garment manufacturing plant. Daisy had sewed before her amputations and thought that she would like to work in the plant. With no feet, Daisy could not operate the standard foot pedal on an industrial sewing machine. The employer allowed a sewing machine to be modified to meet Daisy's needs. By replacing the foot pedal with a pneumatic cylinder and providing a head control at a cost of about $400, Daisy was able to control the machine and still have her hands free to manipulate the garments. Soon after working with her modified machine, Daisy became one of the fastest operators in the plant.

"Horse" had been a lineman for a cable television company for about 7 years before he fell from the top of a telephone pole, broke his back, and became a paraplegic. After his rehabilitation, Horse's employer wanted to retain a good employee. After a few weeks working in the warehouse Horse decided what he really wanted was to be back on top of the telephone poles. Many of the linemen used "bucket trucks" to work up high. Horse demonstrated his ability to pull himself up into the bucket. Using his long leg braces, he was as functional as anyone else standing in the bucket. About $3,000 worth of modifications to the truck and some job restructuring enabled Horse to be as efficient and productive as any of his fellow workers and allowed him to continue to perform the job he enjoyed and was trained to do.

David is a young man who was born with arthrogyposis. This condition limits David's mobility, endurance and affects his manual dexterity. David began working at home lacing snowshoes. He used a holding fixture provided to him by the company to hold the snowshoe frames while he laced them. Because the fixture held the snowshoe rigidly, David was forced to continue walk around the frame in order to pull the laces tight. This constant motion and standing affected David's endurance such that he could not work at full productivity. A new holding fixture was designed and fabricated at a cost of $450 that allowed David to rotate the snowshoe, thus enabling him to sit on a stool. Sitting on the stool and bringing the snowshoe to him, enables David to work a full day and earn competitive wages.

The prospect of legislation enabling the development of rehabilitation technology services for people with disabilities of all ages is very exciting and one that is most welcome by the Vermont Rehabilitation Engineering Center and Rehabilitation Technology Services. In considering such legislation a number of issues should be addressed in order to insure quality services are provided in an efficient and cost effective manner by competent people.

"Acquiring appropriate technology" has greater implications than simply providing the funds to purchase commercially available equipment. If purchasing commercially available equipment was the only problem it could be simply solved by allocating a given amount of money for each person with a disability. However "appropriate" imposes a number of caveats that include providing the services necessary to identify and support the technology that will most effectively and efficiently solve a person's problem. Information, evaluation, training and maintenance services that go beyond traditional medical and rehab models and include specific technology expertise must be provided to insure the appropriateness of the technology. None of the examples provided above would have been possible if we were dependent solely on commercially available products.

Much has been said about the difficulty in bringing good ideas for adaptive equipment to commercial realization. Issues such as the limited market size for many devices and the cost to bring a product to production prevent many of these devices from being commercialized. "Reinventing the wheel" is a common activity in the present dissonant network of service providers. A focus of legislation to provide technology assistance must be in finding new ways to disseminate the essence of the technology, i.e. the design and engineering, for those products that have been

proven useful but will not be commercialized such that it can then be implemented locally. Custom modifications to address individual needs can easily be performed. Networks should be developed to share the engineering so that it does not have to be duplicated.

Information systems such as ABLEDATA and JAN have contributed significantly to the dissemination of information about adaptive equipment and solutions to job accommodation problems. The effectiveness of these systems are enhanced when used in conjunction with technology service delivery models. Providing a person with information about the availability of certain adaptive equipment does not necessarily insure that the most appropriate device will be selected.

Evaluation services performed by individuals or a team that have expertise in the application of technology must be an integral part of any service delivery system intended to provide appropriate technology assistance.

While technology must always be provided in a team atmosphere, what must set that team apart from traditional models is the inclusion of a technologist. Technologists may have different expertise. This expertise may range from the ability to identify commercially available adaptive equipment to the design and implementation of modifications and custom equipment. The training required to perform these functions vary from attending workshops and seminars to having an engineering degree. Legislation to develop rehabilitation technology services must recognize the need for personnel trained at all level of expertise. Much emphasis has been placed on raising the awareness and training of professionals working with people with disabilities. A number of training programs have been funded by RSA for this purpose including a rehab technologist program at the University of Wisconsin-Stout. While these programs are extremely important in the effort to provide technology assistance there is an obvious need for the training of rehabilitation engineers. At the present time there is a paucity of training programs in rehabilitation engineering. Legislation to establish rehabilitation technology service programs will significantly increase the need for technologists, especially rehabilitation engineers. The current shortage of engineers in the service sector will become extremely acute unless a concerted effort is made to establish training programs to produce these professionals.

Funding sources are currently available for adaptive equipment. Medicaid, Medicare and agencies such as the state Vocational Rehabilitation agencies have long provided "durable medical equipment" and adaptive equipment meant for vocational goals. Even present rehab engineering programs can usually get many types of "hardware" paid for. Problems arise in funding the support services, including evaluation, training and maintenance of the adaptive equipment. Legislation to establish technology service programs must address the need to "fill in the gaps" of the present adaptive equipment delivery mechanisms and not duplicate it.

The provision of rehabilitation technology services raises a number of issues that must be addressed in order to protect the health and safety of the clients of these services. Two such issues are certification of professional service providers and liability insurance for providers.

At the present time there is no way to identify a "qualified" rehabilitation technology service provider. No certifying body or certification exists. A consumer of technology services is sometimes faced with playing a shell game in order to identify a qualified, competent provider. The expansion of service delivery programs with the concomitant infusion of monies makes the identification of qualified personnel most important. Organizations such as the Association for the Advancement of Rehabilitation Technology should be utilized to develop standards for the qualifications of personnel working as rehabilitation technologists. These standards must be national in scope to avoid the obvious problems that would occur if practitioners served more than one state, each with its own requirements.

The lack of liability insurance for many assistive technology providers presents some major problems, not only to the providers themselves but to their clients and society in general. Without liability coverage, providers are often times denied work. Government agencies, i.e. state vocational rehab agencies, may require a provider to carry insurance as part of a contract agreement. The single biggest problem with the lack of liability coverage for assistive technology providers is the lack of protection afforded the consumers of these services. With almost anyone being able to call themselves a provider of assistive technology (due to lack of certification) the competence of a provider may be unknown. Without the provider having liability coverage there would really be no recourse for the consumer should something go wrong. It would benefit both providers and consumers if the issues around liability insurance were addressed.

Just as the Pratt-Smoot Act of 1931 provided for the distribution of talking books for the blind it is hoped that legislation now being considered will expand the avail-

ability of all types of technologies for all people with disabilities. The benefits of technology to the lives of persons with disabilities have been clear for some time. The time is right to enable the development of comprehensive rehabilitation technology service delivery models through legislation.

We at the Vermont Rehabilitation Engineering Center for Low Back Pain and Rehabilitation Technology Services support this legislation and are committed to doing whatever we can to help bring these concepts to fruition.

Thank you again for this opportunity to express our views.

Mr. OWENS. Excellent testimony, Jerry.

Thank you.

Do you have any questions?

Mr. JEFFORDS. I have a couple of questions. Unfortunately I have to leave at noon, so I appreciate very much the accommodation at this point.

How many similar businesses to yours do you know of in the country?

Mr. WEISMAN. In the country?

Mr. JEFFORDS. That's right.

Are there a lot of them?

Mr. WEISMAN. No.

I was one of the first to develop a private rehabilitation engineering firm on an entrepreneurial level. That was quite a few years ago.

Depending on how you interpret rehab technology, and exactly what it is, the estimate is anywhere from a couple of hundred to four or five hundred in the country.

Mr. JEFFORDS. How do you exist economically?

Mr. WEISMAN. On a fee per service basis. We have a contract with the State rehab agency, with the Handicapped Children's Services. We provide services to just about anybody on a fee to service basis.

Mr. JEFFORDS. Is there any exchange network among similar businesses to share your innovative and common-sense devices?

Mr. WEISMAN. The most appropriate is RESNA, the Association for the Advancement of Rehab Technology.

Mr. JEFFORDS. And how successful is that?

Mr. WEISMAN. It's been pretty successful.

It's about the only one in the country where anybody interested in technology can get together and deal with the issue of technology around rehab. Membership is growing, and I'm sure that Alexandra can say a lot more about it.

It's growing because the interest in technology has grown. The society has grown, and its services to its constituents have grown.

Mr. JEFFORDS. I asked the last panel about the spectrum where you have a large number of people with similar disabilities, and you can make it commercially feasible.

The other end of the spectrum—the individualized matters that you discussed—what do we need to assist you and others in providing the very expensive individualized services for individuals that have a disability which only a few have in the country?

Mr. WEISMAN. First of all, I don't think it's necessarily an issue of expense. A lot of times it's just the availability of the service. A lot of times the service isn't available. If it was available, in and of itself it wouldn't be very expensive. The problem is in that availability.

The advantage of having the comprehensive rehab technology services as you're suggesting in the legislation is that technology—a lot of it can benefit almost any kind of disability.

If you have a machine shop to modify and build adaptive equipment, that machine shop can make things for people with cerebral palsy as well as it can make things for amputees and so on.

The technology resources that exist can be applied to almost any disability. It's that we're hoping will come from that legislation—the availability of those services.

Mr. JEFFORDS. Thank you very much.

Mr. WEISMAN. Thank you.

Mr. OWENS. Just one question, Mr. Weisman.

Do you find that in adapting devices for individuals, you have hit upon certain devices that can be patented and reproduced in large quantities for large numbers of people with the same kind of problem?

Mr. WEISMAN. Less often than I find that the same technology can be applied to a number of other people.

I think there's a middle step in going from individual customized pieces of equipment to the commercialization of that equipment. And that interim step is making the engineering and design available to anybody.

In that case, if I design something the design and engineering part of that is usually the most expensive part of it. If that can be disseminated amongst everybody else involved in the field, then they can use local resources to implement it and fabricate it.

A rehab engineer needs to design it, but a rehab technology service doesn't necessarily need to fabricate it. You could go to a local machine shop or to a volunteer and ask, could you please modify this, or build it?

The problem is getting that information in terms of machine drawings, or enough information to fabricate it to the people who would recognize the need for it, like therapists. They could then bring it to a local resource and say, here. Could you please make this for me? Without understanding exactly what it is.

To answer your question directly, no, I haven't run across very many things that I've designed that could ultimately make me rich because it's going to go into commercialization. On the other hand, I have made quite a few things and know from others in my field that there are things that I've done that would be applicable to other people.

Especially that head control that I showed for the sewing machine. That originally came from Wichita, since they used the same thing for someone with one hand to operate a lathe. I knew about that and used that in our design to modify the sewing machine.

Mr. OWENS. How many people do you employ?

Mr. WEISMAN. Right now? Three.

Mr. OWENS. Are they all engineers?

Mr. WEISMAN. No, I'm the only engineer.

Mr. OWENS. You're the only engineer?

Mr. WEISMAN. We use students from the University.

Mr. OWENS. Thank you very much.

Mr. WEISMAN. Thank you.

Mr. OWENS. I want to thank you, Ms. Enders and Dr. Boardman, for your indulgence of our time problem.

Ms. Enders.

STATEMENT OF MS. ALEXANDRA ENDERS, PROJECT MANAGER, REHABILITATION ENGINEERING DELIVERY PROGRAM, ELECTRONICS INDUSTRY FOUNDATION

Ms. ENDERS. It's my privilege to present testimony on the development of rehabilitation technology.

I'm an occupational therapist, and the project manager at the Electronic Industry Foundation for a NIDRR-sponsored grant investigating issues around technology service delivery.

I am also the editor of the Rehabilitation Technology Source Book.

I'm testifying today on behalf of RESNA, the Association for the Advancement of Rehabilitation Technology.

As you've heard this morning, advancing technology is providing disabled people with advancing opportunities for increasing independence and self-fulfillment. Capitalizing on this promise of emerging technologies, a systematic delivery system must be available which could provide the average disabled person the ability to comprehensively identify personal needs for technology, to review the technology that exists in the field, and to purchase equipment so that costs do not produce an unbearable hardship.

The bottom line is that without a delivery system, disabled people do not get the needed technological support. They may get products, but without a service delivery system, they do not get the support that they need to use those devices effectively.

Until very recently, the emphasis has been primarily on the equipment, as strongly influenced by research and development activities. Not enough emphasis was placed on the delivery process. Little recognition is given to the ongoing nature of a disabled person's need for technological support.

Equipment was and still is often viewed as a one-shot event. This attitude is reflected in the policies of many of the sources for funding of assistive technology.

To get a little of the history, people have been using devices to compensate for impairments since well before written history began. The modern history of assistive technology begins in the 1940's with the post-World War II R&D in the field of prosthetics.

My written testimony describes some of this R&D work. Technology became part of the emerging R&D process in this country. The medical rehab system in the 1950's and 1960's documents creative attempts to apply adaptive equipment, although the technology itself was usually quite limited.

Since the early 1970's, when research funding was significantly expanded for rehab engineering, the quantity and the quality of available equipment has markedly improved. Abledata, a database of commercially available rehabilitation equipment, now lists over 15,000 products from over 1,800 manufacturers.

No one would claim that this change was all brought about by the research funding, but this funding had a wonderful direct influence and possibly an even greater influence indirectly.

When you consider future R&D appropriations, it's vital that you consider these present benefits of R&D activities.

The most important and direct benefits are the development of people resources. Many individuals who started out in R&D are now the pioneer clinicians in this field, and the entrepreneurs in industry. R&D promoted heightened awareness of the field through its exchange of ideas, meetings, publications and professional education.

There have been exemplary pioneering efforts in the rehab technology service delivery, accompanying R&D efforts. But now the field of service delivery itself is finally gaining some momentum.

RESNA, which was started 10 years ago primarily by leaders in the field of R&D, has dramatically expanded its influence on service delivery in the last four years. A survey done in 1987 lists over 400 programs which identify themselves as providers of rehab technology services, and we know there are many more programs not included on this list.

However, there is another account that must accompany this brief history. It's important to understand how disabled people have actually been getting technology that fits them.

This account is better told by a consumer, so I've attached Alice Loomer's article "Hanging Onto the Coattails of Science." This is the second to last page in my written testimony.

I hope that you'll have a chance to read her poignant description of the difficulties that consumers have had over the years. She's old enough to be able to recount the 50's, 60's, and 70's, in getting their technology needs met, as well as her suggestions for improving the situation.

Today, different frameworks could be used to describe the current state of the art in delivery systems technology. The most realistic approach is to admit that there really is no system. Uncoordinated third-party reimbursement drives both the distribution and development processes. Public policy related to reimbursement is most often categorically tied to age.

I've included a chart, attachment two, the last page on my written testimony. This depicts the current developments of the assistive technology service delivery systems for people of all ages, and varying levels of service intervention.

It's interesting to note that even though we know there are disabled persons of all ages in each of these categories, service delivery systems, as you can see on the chart, seem to target only one age group per category. This chart shows the gaps in the delivery system, and also explains some of the many problems why information on the products and general information is not getting to consumers.

This also explains why manufacturers have a very difficult time in reaching consumers, when only three of the six distribution channels have been developed.

Systems have not really developed within any age group to provide a continuum of service intensities to match the continuum of disabled people's needs for technology.

This matter deserves further analysis, and may be one reason why there are so many unmet needs, despite the fact that there are a growing number of programs relating to technology provisions.

This could also be the prime reason that there is so much difficulty transitioning between systems. We are all talking about disabled people, but we're not discussing the same types of disabled people or the same types of intervention needs.

Is there any question that frustration would exist when policymakers, for example some special education and vocational rehabilitation, tried to agree on some common agenda related to assistive technology? They're not talking about the same types of disabled individuals.

I believe that it's time to acknowledge that we're all behaving as the proverbial blind men who are describing the elephant from different perspectives. We must recognize that the part each of us has our hands on is not the whole critter. It's time to discuss the whole system for technological support for all disabled people from cradle to grave.

I'm particularly concerned that our older citizens be included in all discussions related to assistive technology. Policy and research allocations for assistive technology for older, functionally limited Americans and for younger Americans with disabilities are clearly connected. Whichever group precipitates a change, both groups will benefit or suffer.

We no longer have the luxury of pretending that these systems do not at least indirectly influence each other.

A special delivery system must be supported with responsive payment mechanisms. The complex net of payment coordination must be coordinated and simplified. Disabled individuals of all ages share access to financial support as may be appropriate and necessary in order to provide a lifelong continuum of reasonable technology. So that the costs do not provide an inequitable hardship for the disabled individual, this coordination must occur at both the Federal and the State level.

Better quality assurance mechanisms must be established in order to increase the decision making confidence of both these third party funding sources and of consumers themselves, for we know that much of this technology is paid for out of the pockets of consumers.

Without some form of standards and certification, appropriate levels of payments, especially from the more medically-oriented funding sources will never be attained. RESNA considers this to be the single most important issue at this time.

We also highly recommend that training for technology specialists be given high priority. I think that Mr. Weisman spoke to that issue.

In conclusion, the independent living movement, the growing elderly population, technological opportunities and a younger generation who expect technological solutions to be readily available are coming together to generate a very fertile field in advancing the current state of the art in applied technology.

There is an urgent need for the capacity to plan and implement coordinated assistive technology delivery and payment systems that can surmount the barriers imposed by previous legislation and lead to the availability of quality technological assistance which truly meets the needs of each disabled person.

Other countries have dealt with these issues in more comprehensive manners. Developing the mechanisms in the U.S.A. to ensure that disabled individuals of all ages can secure the technology and service that they need is, and will continue to be, an issue that needs consistent Congressional leadership and review.

We urge that legislative initiatives be developed and enacted and that Congress provide the coordination, systems planning and systems implementation that is so urgently needed. The membership of RESNA stands ready to provide further informational support to this subcommittee in its efforts to provide assistive technology legislation.

Thank you for this opportunity to participate in these hearings.

[The prepared statement of Alexandra Enders follows:]

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STATEMENT

PRESENTED BEFORE THE

SUBCOMMITTEE ON SELECT EDUCATION

OF THE HOUSE COMMITTEE ON

EDUCATION AND LABOR

MAY 10, 1988

ON

TECHNOLOGY AND DISABILITY

ON BEHALF OF

RESNA,

Association for the Advancement
of Rehabilitation Technology

Witness: Alexandra Enders

1. Introduction
2. Association for the Advancement of Rehabilitation Technology
3. Background: The Need for a Service Delivery System
4. The Development of the Field of Rehabilitation Technology
5. Current State of the Art in Assistive Technology Service Delivery Systems
6. The Payment System
7. Manpower Development/Quality Assurance
8. Resource Allocation Issues
9. Conclusion
10. List of Recommendations

Attachment 1. "Hanging Onto The Coattails of Science", Alice Loomer. Rehabilitation Gazette. 1982

Attachment 2. Chart: The Current Development of Technology Service Delivery Systems.

Introduction

Mr. Chairman, it is a privilege to present testimony on the development of the field of rehabilitation technology. My name is Alexandra Enders. I am a occupational therapist, and the project manager at the Electronic Industries Foundation for an NIDRR sponsored R&D grant investigating the development of an integrated network of assistive technology service providers across the country. I am also the editor of the Rehabilitation Technology Sourcebook. My involvement with assistive technology started in the community at the Center for Independent Living in Berkeley, California, and has expanded from direct service provision to include research, evaluation and training. I am testifying today on behalf of RESNA, the Association for the Advancement of Rehabilitation Technology. I am a founding member of RESNA, and currently on the Board of Directors and a member of the Executive Committee.

Association for the Advancement of Rehabilitation Technology

RESNA is concerned with transferring science, engineering, and technology to the needs of persons with disabilities. Our Association and the nearly 1000 individuals it represents welcomes the opportunity to comment on issues related to assistive technology for individuals with functional limitations. Our members are rehabilitation professionals from all pertinent disciplines, manufacturers, providers and consumers. Our goal is to promote and support the research, development, dissemination, integration, and utilization of knowledge in rehabilitation technology and to assure that these efforts result in the highest quality of service delivery and care for all disabled citizens.

Background: The Need for a Service Delivery System

Advancing technology is providing enhanced opportunities for increasing independence and life fulfillment for people with disabilities. In order to capitalize on the promise of these existing and emerging technologies, a systematic delivery system must be available which can provide the average disabled person the ability to:

- o comprehensively identify personal needs for technology,
- o review the technology that exists in the field,
- o purchase equipment so that costs do not produce an inequitable hardship.

Rehabilitation technology includes not only the devices but also the systems which people use to obtain technological support. Until very recently, the emphasis has been primarily on the equipment, and strongly influenced by research and development (R&D) activities. The orientation has been "market push". As the equipment was developed, attempts were made to push it into the marketplace. Not enough emphasis was placed on the delivery process; in large part due to the lack of funding. Additionally, little recognition was given to the ongoing nature of a disabled person's need for technological support. (One may only need to learn to drive once; but if one needs an adapted vehicle, one will probably continue to need adapted vehicles. If one requires a motorized wheelchair, or a communication

device, it is not likely that need will be outgrown.) Assistive technology services frequently do not fit well into our traditional service delivery systems geared to cure, closure, aging out, graduation, or some other fixed endpoint. Significant problems, particularly related to funding, occur for example when transitioning between systems, or when the need for ongoing maintenance and replacement of the equipment occurs. Equipment was, and still is, often viewed as a one shot event, an attitude that is reflected in the policies of many of the sources for funding assistive technology.

Though not often recognized, one of the more important factors for the increased attention given rehabilitation technology in the U.S. is the consumer based Independent Living movement, with Federal legislation supporting equal opportunity for disabled persons and equal education for disabled children. Technological advances helped motivate the Independent Living movement by promising more options, and the more active community-based disabled consumer is now creating:

- a more widely recognized market for equipment,
- societal impetus for change,
- ideas for technological innovation.

However, there has only been a single generation of severely disabled persons who have benefitted from significant technological intervention. We are only now beginning to get a sense of the longer term issues that a comprehensive support system must address -- such as: Where does the next adapted vehicle come from? How do you upgrade computer adaptations to remain competitive in the workforce as more sophisticated technology becomes available? What is a rehabilitation agency's role when former clients find they need financing for subsequent generations of equipment? Should a disabled child be entitled to take her school system purchased communication device home over the weekend?

The Development of the Field of Rehabilitation Technology

People have been using devices to compensate for impairment since before written history. The modern history of assistive technology begins in the 1940's with the post World War II R&D effort in the field of prosthetics. In the United States, much of the framework for national research developed during the 1940s. The structure and philosophy of governmental support of science and technology in the USA can be traced to the 1945 report of Vannevar Bush, called Science: The Endless Frontier (Report to the President on a Program for Postwar Scientific Research, 1945). This report has heavily influenced all of the country's research and development activities, including rehabilitation technology. The research agenda for the field of rehabilitation technology grew out of the agenda of its precursor, the limb prosthetics research program, which can be traced to a January, 1945 meeting in Chicago of medical, scientific, engineering, and administrative personnel of the Allied forces. This meeting was concerned with the care of war amputees and with the improvement of limb prosthesis technology. Federal support of prosthetics research grew out of that meeting as did the Committee on Prosthetics Research and Development (CPRD) of the National Academy of Sciences/National Research Council (NAS/NRC). CPRD effectively guided the research programs in prosthetics and other areas of rehabilitation technology for nearly thirty years through advice to

government funding agencies, through coordination of research efforts (workshops, evaluations, panel studies, etc.), and through information dissemination. The original agenda for rehabilitation engineering/technology research in this country came from this committee (see, Rehabilitation Engineering: A Plan for Continued Progress, NAS, April, 1971). In 1972, a formal program of research and development for rehabilitation technology that included the establishment of Rehabilitation Engineering Centers was initiated, chiefly by the Rehabilitation Services Administration and the Veteran's Administration. Research of this nature (wider than just prosthetics) existed previously on a small scale, mostly funded on a piecemeal basis through field-initiated grant proposals.

The prosthetics research program, begun in 1945, had a revolutionary influence on the limb prosthetics field, and by 1955 this research program was having a major influence on limb fitting techniques and limb prosthesis technology. This positive influence has continued, albeit with less dramatic effect than in the early years when science and technology were so new to the field. However, new and dramatic advances appear on the horizon because computer-aided design and computer-aided manufacturing (CAD/CAM) may revolutionize the field again during the next decade.

The influence of funding research connected with the wider field of rehabilitation engineering has been no less dramatic than it was earlier in prosthetics. The provision of technology had become part of the emerging rehabilitation process in this country. The medical rehabilitation system in the 1950's and 1960's documents creative attempts to apply adapted equipment, though the technology itself was quite limited. In 1972, some technology existed for disabled people--not a lot, and much that existed was of poor quality--but almost no technical equipment existed for persons with severe disabilities, the very persons who needed it the most.

Since the early 1970s, when research funding was significantly expanded for rehabilitation engineering, the quantity and the quality of available equipment has markedly improved. ABLEDATA, a database of commercially available rehabilitation equipment, now lists over 15,000 products from over 1800 manufacturers. No one would claim that this change was all brought about by the research funding but it cannot be denied that this funding had a powerful direct influence through the actual research projects and possibly an even greater influence indirectly. When examining future R&D appropriation levels, it is vital that the benefits reaped from the by-products of R&D activity be factored in. Foremost are the development of people resources and expertise. Many individuals who started out in R&D have become the pioneer clinicians in the field, and the entrepreneurs in industry. R&D provided the development of a heightened awareness of the field, and the basis for interchange of ideas, publications, meetings, professional education, as well as the basis for service and equipment standards.

There have been exemplary, pioneering efforts in rehabilitation technology service delivery accompanying the R&D efforts. However, the field of rehabilitation technology service delivery has recently gained momentum, and more clearly emerged in the past few years. RESNA which was started 10 years ago primarily by leaders in the

field of R&D, has dramatically expanded its emphasis on service delivery in the last 4 years. A RESNA survey done in 1987 lists over 400 programs which identify themselves as providers of rehabilitation technology services, and we know there are many more programs not yet included.

Today, the emphasis is changing from "market push" to "market pull"; more attention is being addressed to the dynamics of delivery systems, and to issues related to funding and financing for assistive technology. A survey done 2 years ago by the Electronic Industries Foundation Rehabilitation Engineering Center clearly indicated that manufacturers are able to provide the assistive technology when a financially based market demand exists. They do not need R&D products transferred to them, as much as they need to be paid for the products they develop. This changing emphasis is also reflected in the evolving nature of the Rehabilitation Engineering Center Program of the National Institute on Disability and Rehabilitation Research. We are seeing more research priority given to delivery system issues such as Equipment Evaluation and Quantitative Assessment, thereby developing a scientific basis for matching an individual with the technological support required.

There is another account, from the consumers perspective, that must accompany this brief history. Given the lack of a coordinated service delivery system for assistive technology, it is important to understand how disabled individuals have actually been getting technology that fits them. However, that account is better told by a consumer. Alice Loomer's article "Hanging Onto The Coattails of Science" (Rehabilitation Gazette, 1982) has been attached (Attachment 1.) so you can read her brief but poignant description of the difficulties consumers have had in getting their assistive technology needs met, as well as her suggestions for improving the situation. As you consider actions that would assist disabled people of all ages to benefit from technological assistance, it is vital to remember individuals like Dr. Loomer, for she is just one of the majority of disabled persons who are in no formalized ongoing intervention system, and may have no need to be, yet she has an ongoing need for assistive technology.

Current State of the Art in Assistive Technology Delivery Systems

The development and provision of technology has long been accepted as an integral part of the rehabilitation process in this country. Artificial limbs and braces, wheelchairs, crutches, etc. have been available to people with physical disabilities for many years. More recently, advances in engineering developments are resulting in more sophisticated assistive devices for disabled people with physical or mental impairments - both congenital and acquired. Individuals with loss of: sitting stability, mobility, verbal expression, hearing and vision, hand function, cognitive awareness, etc. can now substantially benefit from new and emerging assistive device technology. Comparative studies and direct observation have shown time and again the value of assistive devices in providing improved function, increased independence, access to educational/vocational pursuits; and most importantly, a life of economic and personal fulfillment. The major barriers that prevent access to these new technologies for

the vast majority are due to the total absence of, or fragmentation of, the delivery system and its associated payment structure.

There are several different frameworks that could be used to describe the current state of the art in delivery systems for technology for individuals with disabilities. These include categorizations such as: level of need/level of support; society's perception of need: the health/medical/sickness orientation vs the public health/nonmedical/-wellness model. However, the most realistic way to describe how disabled people get their equipment is to admit there really is no system, and that uncoordinated third party reimbursement systems drive both the distribution and the development processes. Since public policy related to reimbursement is most often categorically tied to age, a chart is included (Attachment 2.) depicting the current development of technology service delivery systems for disabled people of all ages and varying levels of service intervention needed. This chart shows the gaps in the delivery system. It is interesting to note that even though there are disabled people of all ages in each of these categories, service delivery systems seem to target one age group per category.

Systems are not developing within <u>any</u> age group that would provide a continuum of service intensities to match the continuum of needs. This matter deserves further analysis. It may be one reason why there are so many unmet needs, despite the fact that there are a considerable number of programs related to technology provision. It could also be one of the prime reasons there is such difficulty transitioning between systems -- we may all be talking about disabled people, but we are not discussing the same types of disabled people, or the same types of intervention needs. Is there any question that frustration would exist when policy makers from, for example, special education and vocational rehabilitation try to agree on a common agenda related to assistive technology for individuals with functional limitations? It may be time to acknowledge that we are all seeing the proverbial "elephant" from totally different perspectives, to take off our "blindfolds" and see what we have our hands on. It is also time to include the "elephant" in the dialogue.

This chart also explains why manufacturers have such a difficult time marketing products to certain categories of people. We know that for certain types of products, the demographics indicate a market should exist. However, with only three of the nine combinations currently available, six potential market channels are still undeveloped, and the disabled individuals who could benefit from this technology remain unreachable.

The older population must be included in all discussions related to assistive technology. Policy and resource allocation for assistive technology for older, functionally limited Americans and for younger disabled Americans is clearly connected, and whichever group precipitates a change, both groups will benefit (or suffer). We no longer have the luxury of pretending that these systems do not at least indirectly influence each other. Other countries have dealt with these issues in a more comprehensive and comprehensible manner. It is time for us to gain a better understanding of real needs, and to devise systems that will provide appropriate community based

support for disabled people of all ages, and with a wide spectrum of needs.

The legislation authorizing the involved agencies and their programs has evolved over time; with varying degrees of concern regarding federal/state coordination and cross agency networking. As a result, we now have a technology delivery system that is plagued with gaps in services; confusing in coverage policies, lacking in continuity throughout the life cycle, with accessibility dependent on disability type, age, or vocational potential or health status. The operational structure is now a mosaic of state and federal bureaucracies that makes equal access and acquisition of timely services extremely difficult for any individual disabled person.

The Payment System

A functional delivery system must be supported with responsive payment mechanisms. The complex mosaic of payment programs must be coordinated and simplified. Disabled individuals of all ages should have access to financial support as may be appropriate and necessary in order to provide a lifelong continuum of "reasonable" technology services so that the costs do not produce an inequitable hardship for the disabled individual.

It is becoming increasingly evident that to derive the potential benefits of assistive device technology for both the individual and society at large, increased financial investments by both the public and private sectors is required. Medicare is the "flagship" of the third party payment system. It charts the course that other agencies, as well as private insurance companies, look to for establishing guidelines on coverage policies and reimbursement procedures. The present Medicare policy related to assistive device technology is defined under Part B as Durable Medical Equipment (DME). In part, the policy states that Medicare is prohibited from paying for items and services "which are not reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member". This policy, designed for a more primitive era of assistive technology, is no longer adequate as disabled people seek to benefit from the potential of: powered mobility, assistive listening devices, speaking machines for the non-verbal, enlarged print for the visually impaired; as well as obtain increased access to more traditional assistive devices, such as, toileting and dressing aids, improved wheelchairs, feeding aids, and specialized seating devices -- all designed to increase the independence and self-fulfillment of persons with chronic disabilities.

The technological support needs of an individual with a functional limitation should be met with the least stigmatizing, most reasonable equipment available. In some, perhaps many, cases the most suitable and effective techological solution is available as a mass market product. Current third party reimbursement policies frequently prohibit payment for off the shelf consumer products, even when these can be shown to be [1] equally or more effective, [2] less expensive than a strictly disability oriented product, [3] less stigmatizing for the disabled person to use.

The current delivery system for assistive technology is based in or heavily influenced by the medical model and its focus on sickness. To prevent abuse in the medical system, policy has tried to ensure that services and equipment would not be desirable to non-sick people. The people who need assistive technology often do not fit into this model well. Most are not sick, yet they need compensatory technology to acheive equity with non disabled peers.

Until there is a broader societal shift in how disablity is perceived and compensated, public policy can at least remove the barriers to securing needed and currently available technology.

One economic barrier that should be reevaluated is the present insistence that mass market consumer products are outside the inventory of reimbursable assistive technologies. Even in service systems that are allowed by existing policies to purchase regular market products, there is a genuine reluctance to do so.

Medicare payment policies are primarily designed to support the medical needs of beneficiaries with acute health care needs, who may need a product for a limited period of time. The dominant philosophy is to purchase or rent low cost equipment. This may be appropriate for a segment of the disabled population, but is totally inadequate for those with permanent lifelong disabilities, whose needs may transcend traditional definitions of medical necessity. It is this latter population that has the greatest potential of deriving the most benefit from assistive device technologies.

Furthermore, individuals with long-term disabilities may have need for multidisciplinary services that can be tailored to meet the unique technical needs of the individual. These needs usually include: information services, comprehensive evaluation, technology provision, follow-up training and a reliable source of maintenance and repair. Too often payment programs do not understand the necessity of related services and/or expect the cost of the services to be included in the price of the device. Yet the reimbursement level is set to cover only the cost of the equipment itself.

As a result of the present special interest legislation, and varying financial curtailment programs at both federal and state levels, we now have a complex patchwork of public and private financial support that is rapidly polarizing towards the largely outdated Medicare DME model (Part B). This fragmented financial support system does not foster the development of coordinated services that can systematically provide access to appropriate assistive technology that should be consistent with an advanced technological society.

A major concern at this time is whether federal legislation, combined with federal/state/private sector partnerships, can be evolved that will ameliorate this critical social and administrative deficiency in our delivery system and its financial support structure. Many options exist for the development of effective models for the provision of rehabilitation technology services. There is no single model, however, that will meet the needs of all individuals with disabilities or those of a particular agency. Comprehensive planning between agencies is needed to identify which service delivery options may work best for a given state or region. Multi-agency government

and private sector participation is essential, especially at the statewide delivery level. We recommended that legislative initiatives be developed and enacted that will foster these partnerships in the future, and that Congress provide the authority for coordination, systems planning, and systems implementation.

Manpower Development/Quality Assurance

Better quality assurance mechanisms must be established in order to increase the decisionmaking confidence of both third party funding sources and consumers themselves. Without some form of standards and certification, appropriate levels of payment, especially from the medically oriented funding sources will never be attained. The present situation is a Catch 22 - no funding for services without standards, no standards without service delivery track record on which to base standards. RESNA considers this to be the single most critical issue, one which requires immediate attention.

Clearer role and function definitions of the personnel who are involved in service delivery and direct implementation of rehabilitation technology are required. Key qualifications and basic competency areas need to be identified and used as a basis for developing certification guidelines for rehabilitation technology personnel. This quality assurance concern should be approached from a national perspective. It is recommended that legislative mandate be given for an indepth study of the development of standards and certification procedures related to rehabilitation technology service delivery.

Manpower development requires that individuals be trained to purchase as well as to provide assistive technology. A priority ranking of critical needs by state vocational rehabilitation agencies placed training as the most important issue faced in the use and application of rehabilitation technology (Institute on Rehabilitation Issues, 1986). Estimates on the amount of training staff have received to prepare them to directly provide or to make arrangements to purchase rehabilitation technology services are very low. This scenario is repeated throughout our public school systems, rehabilitation facilities, aging and health care programs.

Qualified technology specialists to work within a coordinated delivery system are urgently needed. Existing training institutions will respond to these training requirements if the financial incentives are made available through the existing granting process. We recommend that training for technology specialists be given high priority. The capabilities of rehabilitation technology that exist today and the promise of future developments for persons with disabilities depend on the availability of qualified personnel. We currently have extensive technological resources which are not being effectively provided to many of the millions of Americans needing assistance. Efforts to enhance the use and application of rehabilitation technology must include provisions for meeting these critical training needs.

Training of personnel to deliver rehabilitation technology services must be approached on at least a two-fold perspective. Clearly, the need for undergraduate level or advanced training of service delivery personnel in the application of rehabilitation technology is

apparent. This represents only a partial answer, however, to the manpower needs and, at best, is a long term solution since the capability to graduate specialized, trained professionals is still very limited. On an immediate short-term basis, the need to train existing staff must be provided. A comprehensive series of in-services and extended workshops must be available to the wide spectrum of personnel who are involved directly in the provision of services to individuals with severe disabilities either as direct service providers or purchasers of these services. The term "purchasers" refers both to professional staff such as vocational rehabilitation counselors, special educators, administrators and others who are involved in recommending or utilizing rehabilitation technology services, and also directly to disabled consumers themselves.

Meeting the training demands for service delivery personnel for rehabilitation technology is a complex and challenging task. Planning to meet these needs should include active involvement by consumer groups and professional associations. The following are major issues that should be considered:

1. Provision of a coordinated program of state and regional training activities to develop a general awareness of rehabilitation technology for existing rehabilitation, health and human service, education and private sector staff.

2. Support for the expansion of existing long-term training programs and the development of additional programs to insure a supply of trained, well-qualified personnel.

3. Implement a regional network of advanced training activities designed to upgrade the skills and capabilities of rehabilitation technology service providers.

Resource Allocation Issues

Technology must be viewed in context. Resource allocation decisions are influencing the individual's ability to select the best combination of options for community-based living. A piece of hardware is not the only way to solve a problem. It is one option. Others include: personal help, learning new skills, adapting the environments, redefining the problem. It would be unlikely that anyone but a "techie" would approach an everyday living problem by asking "What gadget can I get to solve my problem?" Most of us look at the range of possible options, determine the tradeoffs, the resources available, then make a decision. However, where technology is concerned, we already are learning to write reimbursement documentation for assistive technology in terms of cost reduction/effectiveness (e.g., if this widget is provided, it will reduce the need for attendant care services). It will indeed be unfortunate if supportive services which should be considered in combination (personal assistance + technological assistance + environmental adaptation + training/retraining + community-based support system) are seen as discrete alternatives to each other (personal assistance + technological assistance + environmental adaptation + training/retraining + ????). These issues can be seen most clearly around technology because it is so tangible, but it is clear that similar issues exist in all the

supportive services connected to what the medical model might call "chronic care needs". We do not suggest simply providing more of anything; but to carefully look at how and what is being provided; and why it is being provided (or not being provided).

It is critical that players in all areas of this complex puzzle begin working together to avoid fragmentation and the inevitable turf battles that will result if these services are pitted against each other. Denial of services is clearly one way to reduce costs. We are already finding that many of the types and combinations of services and products needed by disabled persons are effectively excluded from reimbursement.

Conclusion

The independent living movement, a growing elderly population, technological opportunities, and younger generations who expect technological solutions to be readily available, are coming together to generate a fertile field for advancing the current state of the art in applied technology. There is urgent need for the capacity to plan and implement coordinated assistive technology delivery and payment systems that can surmount the barriers imposed by previous legislation and lead to the availability of quality technological assistance which truly meets the needs of each disabled person.

The membership of RESNA stands ready to provide further informational support to this Committee in its efforts to develop assistive technology legislation. As an association comprised of rehabilitation professionals, educators, manufacturers, suppliers, and consumers, we feel well qualified to participate in this landmark process.

LIST OF RECOMMENDATIONS:

1. Funding levels for rehabilitation engineering/technology research and development need to be increased. When examining future R&D appropriation levels it is vital that the benefits reaped from the by-products of R&D activity be factored in. Foremost are the development of people resources and expertise. Many individuals who started out in R&D have become the pioneer clinicians in the field, and the entrepreneurs in industry. R&D provides the development of a heightened awareness of the field, and the basis for interchange of ideas, publications, meetings, professional education, as well as for service and equipment standards.

2. There is urgent need for the capacity to plan and implement coordinated assistive technology delivery and payment systems that can surmount the barriers imposed by previous legislation and lead to the availability of quality technological assistance. A major concern at this time is whether federal legislation, combined with federal/state/private sector partnerships, can be evolved that will ameliorate the critical social and administrative deficiencies in our delivery system and its financial support structure. Comprehensive planning between agencies is needed to identify which service delivery options may work best for a given state or region. Multi-agency government and private sector participation is essential, especially at the statewide delivery level where many of the public funds are expended on technology. We recommend that legislative initiatives be developed and enacted that will foster these partnerships in the future, and that Congress provide the authority for coordination, systems planning, and systems implementation.

3. Systems are not developing within <u>any</u> age group that would provide a continuum of service intensities to match the continuum of needs. This matter requires further analysis.

4. The older population must be included in all discussions related to assistive technology. Policy and resource allocation for assistive technology for older, functionally limited Americans and for younger disabled Americans is clearly connected, and whichever group precipitates a change, both groups will benefit (or suffer).

5. Better quality assurance mechanisms must be established in order to increase the decisionmaking confidence of both third party funding sources and consumers themselves. Without some form of standards and certification, appropriate levels of payment, especially from the medically oriented funding sources will never be attained. RESNA considers this to be the single most critical issue, requiring immediate attention.

6. We recommend that training for technology specialists be given high priority. The capabilities of rehabilitation technology that exist today and the promise of future developments for persons with disabilities depend on the availability of qualified personnel. We currently have extensive technological resources which are not being effectively provided to many of the millions of Americans needing assistance. Efforts to enhance the use and application of rehabilitation technology must include provisions for meeting these critical training needs.

Hanging Onto The Coattails of Science

by Alice Loomer, Ph.D.

ATTACHMENT 1.

The gulf between science and the disabled is heartbreaking. Modern technology is capable of making the blind almost as if they could see, the deaf as if they could hear, and us as if we could walk. If they have the actuators and servomechanisms to walk a LEM on the moon, they also have the hardware to walk (and climb and sit) a quadriplegic on earth by automating braces and crutches, for example. But the gap between what is possible and what is likely will continue, for many reasons (some of which we can, perhaps, change).

We are brainwashed by the conventional. We often humbly accept what is as what must be. Starting one's thinking from scratch is very hard. It took me 40 years to realize I didn't have to put up with miserable tucked-in bedclothes. Now, I sleep comfortably, my way, with a firmly anchored bottom sheet and a small light weight throw that's easy to handle.

The disabled, by and large, have been given little knowledge of science and technology, and have been so little encouraged in inventing, that they cannot design for themselves nor guide those who could. The same is often true of rehabilitation centers. Even in one's own town, there are craftsmen and experts ranging from telephone technicians to model plane clubs (experts in remote controls) whose help is lost because neither the disabled nor their rehabilitation centers see the possibilities.

Scientists and technologists have trouble picturing our real needs in practical (and cheap) terms, as they also do with those of the Third World. They are as brainwashed by the esoteric as we are by the conventional.

Manufacturers and distributors. Not only are we a very tiny market (how many bicycles and motorcycles to one wheelchair?) but for promotional and sales and service purposes, manufacturers need products so complicated that they have exclusive rights.

We, on the other hand, need equipment so simplified that it can be made from cheap, readily available parts and serviced by local repairmen, family, friends, neighbors (or oneself).

What's to do about it? Perhaps a lot more of what many readers are doing right now:

- Whenever we see a product that's clearly not user-oriented (like most reclining backs and adjustable foot boards), or equipment that could have used standard parts but didn't, we can protest to manufacturers.

We can keep reminding governments that simple design faults that bar us from independent living are costing the country millions of dollars annually. The conventional electric wheelchair is an engineering disgrace, as well as being thirty years behind the times. No appliance outlets. No provision for heated foot blankets and jackets, and not even a heated cover for one's driving hand. No user-operated back and leg rests. No power loading and unloading. No quick, easy handyman repairs.

Dr. Loomer is a mixture of things: rehabilitation psychologist, 10 years, New York University; then psychotherapy practice in New York, writer; now partly retired consultant, Halifax, Canada; and, since age 9, full-time schemer, improviser, inventor, and finagler to beat the rap of polio and lead her own life, her way.

- We can write to science, technology, and manufacturing journals and conventions asking them to be alert to any of their new developments that might have spin-offs in our direction. We ourselves can be alert to new discoveries, inventions, and products intended for other uses.
- We can learn to improvise, invent, supervise, or do more of our own construction. Like most people with polio, that most whimsical of diseases, I have an unreasonable pattern of weaknesses. If limited to commercial equipment, I would have been very helpless, so we (my family and I) were forced to develop all kinds of things: kitchens, hand controls, van lifts, even urinals. (There's nothing like a paper coffee cup, a small garbage bag, a bunch of Kleenex, and a rubber band!)

My first wheelchair was made by my teenage brother from a kitchen chair and his old bicycle — it worked fine until I outgrew it. My last is concocted out of an old E and J frame, a set of motor wheels installed by an apartment handyman, and wiring, controls, figured out and put together by me. Its craftsmanship is deplorable, but it's the only wheelchair that could have kept me away from nursing homes and attendants. It stays on the road. (In twelve years, the longest it has ever been broken was 24 hours, once.) I made it. So I know how to fix it. It's easy to add conveniences.

I may have had to grit my teeth, I may have had to drive myself to learn about motors and wiring and relays. I may have failed almost as often as I succeeded, but I have equipment that fits me.

So I guess I'd better keep on saying, "There ought to be a way," and beating my brains out to find my own little bridges to science and technology.

Dr. Loomer is a mixture of things: rehabilitation psychologist, 10 years, New York University; then psychotherapy practice in New York, writer; now partly retired consultant, Halifax, Canada; and, since age 9, full-time schemer, improviser, inventor, and finagler to beat the rap of polio and lead her own life, her way.

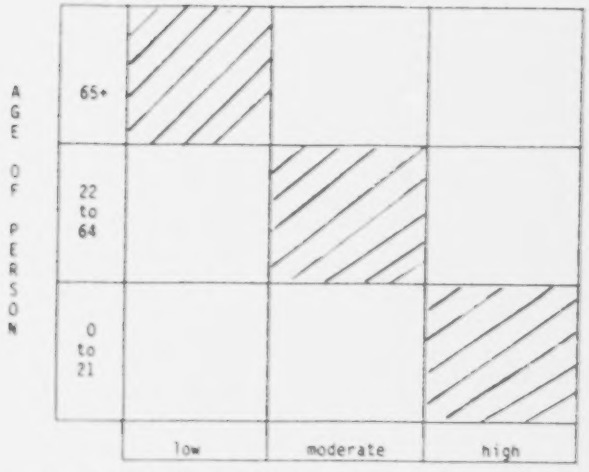
Address: Alice Loomer, Ph.D., 1333 South Park Street, Apartment 1618, Halifax, Nova Scotia, B3J 2K9, Canada.

ATTACHMENT 2.

The Current Development of

TECHNOLOGY SERVICE DELIVERY SYSTEMS

for Disabled Individuals of All Ages and
Varying Levels of Intervention Needed for Technological Assistance



▨ = Technology Service Delivery System(s) exist or are emerging to address this combination of age and need.

☐ = Absence of Technology Service Delivery System to address this combination of age and need.

Note: It is assumed that each individual included here needs assistive technology. The chart demonstrates the varying levels of intervention required to ensure the individual can adequately access the technology he/she needs.

Mr. JEFFORDS. Mr. Chairman, I apologize. I have to leave.

I want to apologize especially to Dr. Boardman. I assure you that I'll read your testimony, and I thank you very much. I'll look with interest on all the testimony that is to follow.

Thank you, Mr. Chairman.

Mr. OWENS. Thank you.

Dr. Boardman?

STATEMENT OF DR. BARBARA BOARDMAN, SENIOR ANALYST, HEALTH PROGRAM, OFFICE OF TECHNOLOGY ASSESSMENT

Dr. BOARDMAN. Thank you.

Is this going to work? Am I there?

I am Dr. Boardman, a physician and senior analyst with the Health Program of the Office of Technology Assessment.

In 1982, OTA, at the request of Congress did a study entitled Technology——

Mr. OWENS. Would you move that mike a little closer, please?

Dr. BOARDMAN. Is that better?

Mr. OWENS. Yes.

Dr. BOARDMAN. Okay.

Since that time, we've been requested to do an update of the 1982 report.

During that past five years, there have been significant changes in the use of high technology. Personal computers and smart appliances are a practical reality for able individuals.

We now ask, how effectively is this new technology being delivered to disabled members of the American population?

OTA has defined technology as the application of an organized body of knowledge to practical purposes. This definition includes not just physical objects but also prophecies and systems.

I underscore that it is not the gadget that defines the technology. It is the knowledge of the user that converts that gadget into a useful tool.

The definition of technology clearly implies that assistive devices must be considered as only part of the foundation that we raise when we build a system of support for disabled individuals. There are four elements that OTA considers to affect the availability of assistive technology.

One, the development of the device or process.

Two, the dissemination of the information—that is, consumers can only use technology if they are aware of it.

Three, delivery. This includes a system that delivers the product to the consumer, trains the consumer in the appropriate use, and maintains the product in working order.

Finally, dollars. Every element of this system has a cost, and the availability of funding to pay for the cost of the device, including the development, dissemination and delivery, is a deciding factor. Simply put, dollars drive the system. If no one pays for it, no one gets it.

Discussions in the 1982 OTA report about research and development generally ring true today. But discussions with those in the field currently indicate that there are additional themes that we should add. Specifically, current discussions indicate that a signifi-

cant amount of assistive technology development involves the innovative adaption of off-the-shelf commercial products, for example, microwave ovens that may be the only technology for individuals with certain motor disorders to cook a meal.

While these are routine items, that would be a very important item for that type of disabled individual.

People items such as Velcro clothing and sneakers can facilitate self-care for an individual who is unable to handle shoelaces.

Because off-the-shelf products are mass-produced, they are much cheaper than the products that are made available for the small disabled market. Unfortunately, funding mechanisms for assistive technology often don't support the use of this cheaper equipment.

Secondly, assistive technology is more likely to evolve when the technology is developed with, not just for, disabled people.

Innovation in assistive technology generally seems to occur in settings where those with technical skills interface with consumers. Such systems are much more likely to focus on appropriate technology including the adaptations that we've described.

Policies to encourage development will be much more effective if they involve the consumer at all points.

With reference to information dissemination, information transfer has been significantly improved in the last five years. But the new information technology has not been fully integrated into the assistive technology delivery system.

What is needed is not simply a database but an information system. Such a system would allow timely and thorough exchange of knowledge, not just the simple listings of equipment.

Criticisms of the current system imply that a more coordinated system could improve information delivery. Certain features are implied, which include:

One, that it should be a unified information network.

Two, that it should be predictably and continuously funded.

Three, that it should incorporate consumer feedback at all points.

Four, that involving information exchanges should be made in several formats. Among that we include conventional formats such as print, interpersonal and hands-on coordination, and electronic media.

Finally, the information should be accessible to the full range of users. Particularly in this system you have to consider its accessibility. Some users will have unusual ways of needing to access information.

With reference to the systems of delivery and dollars. We note that the system which delivers assistive technology to disabled people is inextricably linked with the funding system that pays for that technology.

The disabled individual who hopes to find funding to cover the costs of assistive technology must work his way through a maze of possible public and private funding sources. These include health insurance plans, compensatory insurance carriers, and support programs. For children, educationally focused plans might supply additional resources.

Underscore my saying may provide resources. Eligibility determinations are made on a variety of criteria and vary from State to State. Funding is not guaranteed.

The delivery system in fact reflects the fragmentation of the funding system. Because the funding system is stratified by age, so the delivery system stratification results in some unusual distortions in care delivery. Equipment funded for an educational purpose may only be available in an educational setting, and we've heard that described today.

Equipment customized to a disabled individual in a school setting may not be transferred when that individual graduates and obtains employment.

In many cases, the model for coverage is based on medical necessity. As such terminology may be used to exclude many items that are useful aids to independent living but which are not life-sustaining. These include, for example, communications devices or mobility aids.

To further complicate matters, the systems that fund disability technology vary from State to State. Devices covered in one State may not be covered in another.

There is a general consensus that the current delivery and funding system is difficult to navigate. Interestingly, OTA found a general consensus that a more rational system is possible. Various States have been working on improved models of disability technology delivery. Where there is not uniform agreement on the model of such a delivery system, there are principles that have emerged from this discussion.

One, the current lack of coordination and funding, and the resulting vulcanization of care delivery confuses and frustrates all who use the system.

Two, it is possible to conceptualize a more rational system. Such a system would have to be woven into an integrated disability policy.

The segregation of assistive technology policy from other aspects of disability policy, such as independent living, rehabilitation, income maintenance and health care, will only further fragment the care.

Three, a more rational system would match the level of care to the need of the individual, and would provide easily accessible information.

In theory, all levels of care would be provided when appropriate to disabled individuals.

There is concern that we may now be underserving certain age, income, ethnic, linguistic, and geographic groups.

Four, a more rational delivery system for assistive technology will require the involvement of consumers and the professionals who are willing to work with them. That should occur at all points in the system.

Five, the delivery system for assistive technology must address the issue of maintenance and upgrade. Maintenance and replacement of devices must be considered an implicit part of the cost. If we do not consider that, we are not going to provide useful technology to those individuals.

Next, the issue of coordination of care between various disability support systems has not been adequately addressed. Accounting, ownership, and leasing systems, for example, could be adjusted, so that assistive technology could follow the user, rather than the funding system.

Finally, it must be understood that funding is the system that is now driving care delivery. Policies that rationalize the delivery of assistive technology will have to address the nature of the funding system, both in the private and the public sector.

Thank you.

[The prepared statement of Dr. Barbara Boardman follows:]

TESTIMONY OF BARBARA BOARDMAN, MD, MPH, OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS

I am Barbara Boardman, physician and senior analyst in the Health Program of the Office of technology assessment. I am here today to comment on the use of technology by disabled people.

In 1982 the Office of Technology Assessment (OTA) produced a report for the Congress titled Technology and Handicapped People; in 1987 OTA was asked to update that report with a staff paper. During the past 5 years there have been significant changes in the use of "high technology" by the general public. The personal computer and microchip controlled "smart" appliances have become a practical reality for able individuals in the business and home setting. We now ask, "how effectively is this new technology being delivered to the disabled members of the American population?"

OTA has defined technology as "the application of an organized body of knowledge to practical purposes." (OTA 82 p. 51) This definition encompasses not only physical objects, such as communication devices, but also processes such as vocational rehabilitation and reimbursement systems. It should be underscored that it is not the gadget that defines the usefulness of a technology; it is the knowledge of the user or users that converts the gadget to a useful tool.

For the purposes of this analysis, OTA has primarily focused on technologies designed for and used by individuals with the intent of eliminating, ameliorating or compensating for functional assistive devices, but the definition of technology clearly implies that such devices must be considered as only a part of the foundation we lay when we build a system of support for disabled individuals.

Analysis of factors affecting the availability of assistive technology for disabled individual must address the four factors that bring technology to the user. These factors are:

1. Development of the device or process. The new idea is the first and most obvious step in creating new assistive technologies. Full development of the idea involves applies research, testing and production process development.

2. Dissemination of information about the devices or process. Consumers and the care providers who work with them can only use the equipment if they are aware of its existence and how to get it.

3. Delivery of the device or process. There must be a system that delivers the product to the consumer, trains the consumer in the method of appropriate use, and maintains the product in working order. The delivery system for assistive technology involves consumers and several levels of professionals who evaluate, prescribe, train, and maintain.

4. Dollars to pay for the device or process. Every element of the system has a cost; the availability of funding to cover the costs of the device and of the costs of development, dissemination and delivery will be the deciding factor. Simply put; dollars drive development, dissemination and delivery.

In our analysis we reviewed each of these areas, focusing particularly on issues that have come to the fore since the 1982 report. Many of these new issues are practical problems that arise when innovators have attempted to deliver assistive technology to disabled users.

DEVELOPMENT

Development of a new device or process involves several steps, each built on the step that preceded it. The problem or opportunity is identified. Solutions are applied and tested. Refinements are made and are retested. If the product is to be produced

and marketed commercially, the production processes and marketing system, as well as the device itself, must be developed and tested.

In the 1982 OTA report there was extensive discussion of the issues of research and development (including the role of the federal government and the private sector in such research) and of evaluation, diffusion, and marketing of such technologies. Review of the current literature reveals that while some changes (such as increased facilitation of technology transfer from the Federal government) have occurred in the intervening five years the tones generally ring true for the issues that were sounded. Discussions with those in the field indicate that two additional themes should be added to the discussion.

The initial OTA discussion focused on a model of development that drew extensively on commercial product development for the disabled community. Current discussions (Shane, personal communication; Hallet, personal communications) indicate that a significant amount of assistive technology involves the innovative adaption of generally available commercial products. For example, a microwave oven may be the only safe technology for individuals with certain movement disorders to cook a meal. Velcro closure sneakers can facilitate self care. An off-the-shelf personal computer used with adaptive software may significantly improve the functioning of a disabled person.

Because the products involved are produced on a mass scale the product can be produced more cheaply than products that are custom made exclusively for a small disabled user market. Unfortunately the funding mechanisms for providing assistive technology do not easily facilitate the use of such equipment because of its off the shelf nature.

Implicit in the 1982 report and echoed in the current literature and in comments of practitioners in the field is the concept that appropriate assistive technology is more likely to evolve when technology is developed with, not just for, disabled people. The importance of active consumer involvement for the development of appropriate technologies was heard from all quarters. (Shane, Berkowitz, Heumann.) Review confirms that innovation in assistive technology generally seems to occur in settings where those with technical skills interface with consumers. Policies to encourage development will be more effective if they draw on consumer involvement at all points in the process.

DISSEMINATION OF INFORMATION

In the 1982 OTA report the importance of information dissemination about assistive devices was implicit in the discussions of diffusion and marketing. In the intervening five years the technology of information transfer has been significantly improved, but that technology has not been fully integrated into the assistive technology system. Numerous information sources (including electronic data bases) are listed for disabled individuals and their care providers, but the vast majority of these are small; they focus only on particular subpopulations; systematic surveys of all manufacturers and updates of data are rarely possible. Even the larger systems are considered to have flaws with completeness and timeliness of data. Care givers and consumers note that what is needed is not simply a data base but an information system. Such a system would have to allow timely and thorough exchanges of knowledge rather than incomplete listings of equipment available. Analysis of the problems with current information systems focuses discussion on two areas where fragmentation of the information system occurs: 1) fragmentation of user groups and 2) fragmentation of information formats.

USER GROUPS

Information networks for assistive technology serve several user groups:

1. Manufacturers use these networks for at least two purposes; 1) aid in marketing their equipment, and 2) to get feedback that will allow improvement of the product.

2. Rehabilitation professionals (physicians, occupational therapists, physical therapists and nurses) need information about equipment that will permit appropriate fitting, use, and choice of alternative equipment. They need information on techniques and adaptations of off-the-shelf equipment that will be useful for patients. Availability, cost and funding data will also be necessary.

3. Disabled consumers need the same types of information as professionals but they need a presentation of the material that is appropriate for a lay person.

INFORMATION FORMATS

The format in which information is provided may alter the effectiveness of the information network. Currently, information is transmitted in three main formats, 1) interpersonal 2) print and 3) electronic data. Each has advantages and disadvantages.

Interpersonal communications involve informal (i.e., word of mouth) and formal networks (i.e., conferences, training and teaching, and demonstration projects). This form of information transfer permits hands on evaluation of devices. This hands-on "look and try" method is considered optimal for communicating information and assistive technology. Unfortunately it is a costly and inefficient method for mass communication.

Printed information is cheap to produce and easy to distribute. It is currently the format in which most assistive technology information initially reaches the most consumers and professionals. This information ranges from professional journals through lay publications. Manufacturer advertising is a part of this network. The disadvantages of this format are the unsystematic and incomplete nature of the data presented, lack of direct consumer feedback mechanisms, difficulty with updates of materials and the lack of hands-on experience with the devices.

Electronic information systems (computer data bases) are a new technology which offers the potential for major improvement in the dissemination of assistive technology information. While such systems cannot provide the specific hands on knowledge these systems offer a new format for screening information so that professionals and consumers could learn of new technologies and selectively screen for devices that would be worth further hands on assessment.

In theory, a computer data base could be used to provide information about assistive technology. The completeness of the data base would depend on the mechanism by which data was provided. The information could be updated at regular intervals if new data was provided. Consumer feedback could be collected on all items. A sophisticated system might also include graphic displays.

Unfortunately, the current state of practice does not come close to the theoretical model. Most data bases have been small, and poorly funded. A system of multiple small data bases means all of them have incomplete data. (If there were a single dominating data base, manufacturers might find it easy and useful to contribute information and updates.) Unstable funding inhibits updates. Small budgets preclude feedback analysis and evaluation.

The current information network is an informal one that draws on various data bases (ABLEDATA and the Job Accommodation Network are the most significant of these) and other informal networks of communications agencies that have some responsibilities related to assistive technology. Most of the information is channeled to consumers through various care delivery centers. Because the informal information network focuses on delivery centers it is more likely to involve hands on information delivery. It is also more likely to involve a focus on the patient. There is also a flexibility in the informal network that permits different groups or centers to specialize in particular services. The disadvantages of the current informal system are that the information delivery is remarkably unsystematic and incomplete. Certain subpopulations may be underserved (i.e., rural populations, linguistic and ethnic minorities.) The databases that delivery groups draw on to provide information are also small and incomplete.

Criticisms of the current informal system imply that a more coordinated system could improve information delivery. While an exact model is not available certain features are implied. These basic features of an ideal information transfer system include:

A unified information network; predictably and continuously funded; incorporating consumer feedback;

Involving information exchanges in several forms; electronic data bases, graphic, print, video? conferences of professionals and consumers, demonstrations and hands on evaluations.

Accessible to the full range of users including: manufacturers, professional users, consumers, users whose access is limited by geography, and users whose access is limited by their disability.

DELIVERY AND DOLLARS

The system which delivers assistance technology to disabled people is inextricably linked with the funding system that pays for the technology. Disabled individuals are disproportionately out of the labor force (40% of disabled individuals age 18 to 64 years described themselves as unemployed or out of work in the 1986 ICD

Survey.) The income distribution of disabled individuals is disproportionately low. (30% of disabled individuals not living in institutions, as compared to 14.5% of individuals not limited in activity, were found to have an annual family income of less $10,000 in the National Health interview survey for 1983–1985.) Thus financial issues in general and insurance coverage issues in particular render this population vulnerable.

The disabled individual who hopes to find funding to cover the costs of assistive technology must work his or her way through a maze of possible public and private funding sources. These include health insurance plans (Medicare, Medicaid and private insurance plans), compensatory insurance schemes (workers compensation, long term disability, veterans benefits), as well as support program such as vocational rehabilitation. If the individual is under the age of 18, educationally focused programs may provide additional resources. Resources for assistive technology may be available to a disabled individual through these various programs if the individual is determined to be eligible. Eligibility determinations are made on a variety of criteria, depending what funding system is involved. It is not surprising, given the complicated nature of the system that disabled individuals have difficulty finding services. 54% of disabled individuals studied in the ICD survey reported it was "somewhat hard", "very hard" or "almost impossible" to find out about services available to them.

The delivery system reflects the fragmentation of the funding system. Care is delivered in various settings that may have a medical, educational or social service focus. Because the funding system is stratified by age, so is the delivery system. This stratification results in some unusual distortions in care delivery. Equipment funded for educational purposes may only be available in an educational setting. (Thus, a care giver reports he has patients who can only communicate from 8:00 am to 3:00 pm, Monday to Friday; the communication device stays in the school when the child goes home.) Equipment customized for an individual in the school setting may not be transferred with that individual when he turns 18 and obtains employment.

In many cases (Medicare, Medicaid and private health insurance) the model for coverage is based on a concept of "medical necessity". Such terminology is ambiguous. It may be used to exclude many items that are useful aids to independent living but are not life sustaining, such as mobility aids, communication devices or hygienic items. (Heumann) To further complicate matters the systems that fund disability technology vary from state to state. Devices covered in one state may not be covered in another.

There is a general consensus that the current delivery/funding system is difficult to navigate for the individual and for the care giver. Interestingly there is a fair degree of consensus (Berkowitz, Vanderhaven, Rahl) that a more rational system is possible. Various states, (New York, Florida, Minnesota, Pennsylvania, Wisconsin) have been working on improved models of disability technology delivery. While there is not a uniform agreement on the model of such a delivery system there are principals that emerge from the review as useful focal points for discussion:

1. The current lack of coordination in funding and the resulting balkanization of care delivery confuses and frustrates all who use the system. The system is segregated by age. Any many people believe that if data were available, it is likely that inequities of coverage by geographic, ethnic, racial, linguistic, and disability group would also be uncovered.

2. It is possible to conceptualize a more rational system. Such a system would have to be woven into an integrated disability policy. Segregation of assistive technology policy from other aspects of disability policy, such as independent living, rehabilitation, income maintenance, and health care will only further fragment care. This does not necessarily imply that all disabled individuals need to receive identical services. Rather it implies that these services should be matched to the needs of the individual, not the funding system.

A more rational system would match the level of care to the need of the individual. For example:

Primary technology assistance would involve care that is directly accessible to consumers (i.e. catalog aids to the elderly, off-the-shelf gadgets, do-it-yourself home adaptations).

Secondary level technology assistance would involve some use of the primary care medical system for access to information, fitting or prescription (i.e. home adaptations and living aids proposed by appropriate therapists, Canes/walkers and mobility aids offered by physical therapists in community hospitals, family physician's prescriptions for rehabilitation devices).

Tertiary level technology assistance would involve specially modified, high technology, high cost assistive technology and adaptive environmental systems. These system involve extended analysis by a trained rehabilitation team including rehabilitation physicians, technology consultants such as engineers and allied health professionals.

In theory, all levels of care should be provided when appropriate to all disabled individuals. Reports from some care givers indicate that under our current system certain populations may receive less services. For example, some suggest that the elderly are more likely to get primary level services; while tertiary assistive technology services are more likely to be provided through the pediatric system. In addition, care givers in the field suggest that we may underserve certain income, ethnic and linguistic groups. Finally, the issue of geographic distribution of care is also of concern. Care delivery methods that are appropriate and available in areas of high population density may not be available to the disabled individual in other areas.

No data have been collected on these topics to confirm these reports. Data collection and needs assessment would make a more focused plan for care delivery possible. The issue of equity in service delivery would be better addressed by more accurate data collection. Such data collection could be the first step in realignments of service delivery to address issues of inequity. It is plausible that there are regional variants in need. Accurate needs assessment would be the first step in building regional systems that could address such inequities.

3. A more rational delivery system for assistive technology will require the involvement of professionals who will work with consumers to provide these services. Various existing professions (i.e. rehabilitation physicians, occupational and physical therapists, nurses special education teachers, rehabilitation counselors, social workers) and emerging professions such as rehabilitation engineering will have to find a place in the system. The training and licensing requirements for such professionals have outlined in relation to the emerging system of care delivery. Training programs for such professionals may need to be altered or expanded to fit the changing pattern of care delivery.

4. Delivery systems for assistive technology must address the issues of maintenance and upgrades. Maintenance and replacement of devices must be considered an implicit part of the cost of the device for the disabled individual who needs assistive technology. Support systems that ignore these costs will underrate the cost of assistive technology. (For example, an individual who needs a wheel chair van to get to work will need to have that van repaired and may eventually need a replacement wheel chair van. An individual who needs a personal computer to communicate in a work or education setting may need to upgrade the computer if his old model is incompatible within others being used in his work setting.)

5. The issue of coordination of care between various disability support systems has not been adequately addressed. Accounting and ownership and leasing systems could be adjusted so that assistive technology could follow the user where appropriate.

6. Funding is the system that drives care delivery. Policies to rationalize the delivery of assistive technology will have to address the nature of the funding system both in the private and public sector.

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Mr. OWENS. Thank you.

I have only one or two questions.

Ms. Enders, you mention a database called Abledata. Could you explain a little bit more about how Abledata works?

Ms. ENDERS. Abledata is a database that lists 15,000 different commercially available rehabilitation products. Its development was funded and it is currently not being updated because Federal funding has reached a gap in it.

Mr. OWENS. Federal funding has done what?

Ms. ENDERS. Federal Government funding ran out last summer, and there has been no new contract for anyone to update it.

If it's left unupdated for about a year, we'll see another round, I believe, of information databases where the Feds are going to pay for several different databases to be developed, and then several of them will go out of business when the Federal funding runs out.

Abledata has been around for many years now, and it's become useful because it's gotten a critical mass of products in it.

It is not, as Dr. Boardman says, an information system. It's just a database to be used by someone who's familiar with using databases.

It provides information on the name of the product, the manufacturer of the product, a brief description of the product, range of costs, the year the information was put in.

There is the ability to include evaluative information on products, but there is very little evaluative information available. In most cases, those fields in that database are empty.

There are several different projects around the country looking at how to put on what's called a front end, that would make Abledata more user friendly. This would help translate what those products are to match the need of the disabled individual.

Right now, all it does is what a catalog does—shows you what products are available. It doesn't tell you which ones you need.

Mr. OWENS. Not a single member of the previous panel mentioned Abledata when we asked the question about where they got information from.

Is that because they're all consumers, and Abledata is only used by experts and professionals?

Ms. ENDERS. Well, consumers do use Abledata. Especially when used through a broker—somebody who's more comfortable with using databases——

Mr. OWENS. Well, that's what I'm asking.

Ms. ENDERS. That's right. They tend to——

Mr. OWENS. Who's most comfortable using it?

Ms. ENDERS. It tends to be information people using it.

In reality, none of us really use databases to get a whole lot of information from anything. We call our friends.

It's the sophisticated information professional who would use the databases.

I think that's——

Mr. OWENS. So, it's just as well that the Federal Government stopped funding it.

Ms. ENDERS. No, I think that unless——

Mr. OWENS. They don't use it.

Ms. ENDERS. It's a tool. Abledata is a tool that can be used to compile much other information.

If there isn't some centralized source, which would be the center of an information network, on things that are easily centralizable, like product information, it's—everybody's going to have to be collecting the 15,000 products, the 1,800 catalogs, keeping those in 20 file drawers. That's how many it takes to house the Abledata file catalogs.

If we do that, instead of being able to provide information to information seekers, to consumers, to people in the community, we're going to spend all our time reinventing the wheel. We're all going to be refilling those 20 file drawers.

It's much better to have a central place or system that collects the information on products and lets those of us out in the community use that information combining it with other kinds of supportive information and help package that information so that consumers can use it.

I think that it's really vital that some system be supported at a national level. Since Abledata has got the longest track record and is the most complete of any of the systems, it's a logical place to support it.

Mr. OWENS. It's not friendly, though?

Ms. ENDERS. But you can connect other pieces to that system.

Mr. OWENS. Can make it friendly, huh?

Ms. ENDERS. There are ways to make it friendly. I hope that we will include people.

It's interesting. In the development of Abledata eight or ten years ago, they tried to create information brokers. I had the enlightened idea that if you had a person there, that would help translate that information—take your information request when you called for something, help figure out what you need—they would search that database and then give the consumers the digested information. I thought that would be the most appropriate way to do it.

Well, we weren't quite ready for that eight to ten years ago. I think you'll recall back then that not just in disabilities but in all fields of computer applications, databases were going to solve everything. We would never need people.

Well, I think that we've found out the hard way that's not true. We do need people, translators and interpreters in the middle of some of those kinds of information.

I would hope to see—and would again look at—how brokers could be put back into the system. Some States do that fairly successfully right now.

Mr. OWENS. Dr. Boardman, do you care to comment?

Dr. BOARDMAN. Well, Alexandra and I have discussed this before—actually, just last evening.

I think that when we distinguish between a database and an information system that what we're trying to make clear is that the

database is a place where facts are. But it doesn't exchange knowledge.

That knowledge exchange has to involve many components. In reference to a disability, assistive technology type database, you do need to deal with a whole bunch of issues. You need to deal with regional issues.

For example, a nationalized database is not going to tell you what regional availability is. It's not going to tell you about where you can conveniently get adaptations that may be straightforward.

Regionalization may be one element of it. On the other hand, you hate to lose track of the fact that there is a need for a centralized location for certain aspects of that information.

The other thing that needs to be distinguished is that the information and knowledge network involves different types of information exchange. The print information or the electronic information can give you a description of the equipment, but it's not the same as trying it or looking at it. It's a good place to go for a screen, to find out that there are 15 possible wheelchairs or 8 possible communications devices. Then you will work with your broker to determine which of those you really want to consider trying.

In addition to that, your information network has to include—I think the cutesy term is you've got hardware and software—your liveware. There is really an interaction in terms of engineers exchanging information at conferences, or professionals working with consumers in independent living situations.

That is a very significant part of this information network.

If we really want to fund a good information network, we have to include in it support for those sorts of interactions. So that regional interactions and interpersonal interactions, even at a national level, are included.

Mr. OWENS. Mr. Bartlett?

Mr. BARTLETT. This technology and those sources of that technology—is it a problem of funding, is it a problem of knowledge, is it a problem of having the engineers to adapt? Where would you judge there is the most significant barrier to the use of that technology by persons with disabilities?

Dr. Boardman?

Dr. BOARDMAN. I get to start.

I think that if I could rank three, and not just go for one, the first barrier is going to be funding. If it's not funded, there's no impetus for the system to develop. The funding costs at some point could include the costs of dissemination of information and so on.

If you have funding, you can create a demand pull. In fact, we've seen that there's a lot of good technology that can be developed. There are a lot of creative engineers, creative professionals and creative consumers.

The problem is supporting that cost.

Second to that—and I guess I would rank it separately because it's so important—is the coordination of the systems for service delivery. A funding system has to make it possible for the individual to find their way through it.

Care is so fragmented that this in itself, independent of the funding, is a significant barrier.

I would rank the information system third. That is something that comes up as a clear problem. People need information, and that has to be facilitated.

Mr. BARTLETT. Mr. Weisman?

Mr. WEISMAN. I agree with Dr. Boardman. She has said it as well as I could.

The funding issues are certainly there. It's the coordination of the service providers—that's something I alluded to in my testimony.

This technology exists, and the provision of technology services goes across a lot of disabilities. Lots of time, what happens is that each interest group develops some type of program to develop their type of technology, whether it is because of a certain disability or a certain funding source.

Special education deals with their problems. Vocational rehab deals with their problems. Medicaid deals with their problems. All too often in a State with those three, a lot more agencies don't talk to each other and don't know what each other is doing. They are frequently with the same clients—if not at the same time, then in succession.

Special ed will deal with someone until they're 21, and all of a sudden they're voc rehab clients. Nobody knows what anybody else is doing.

The technology service provision can tie those things together, because this is in some ways a generic thing that can go across all these things.

Mr. BARTLETT. Do you concur with Dr. Boardman that a financing of that would shake a lot of the problems out of the system?

Mr. WEISMAN. I think it will shake a lot of problems out.

I think it will also create some problems.

I think that—I don't know if I would rank those priorities in quite the same way. I think that coordinating things might be even more important, initially, than the funding issues.

But that's coming from someone who sees the availability of some of this. I don't think it's enough, as you've just heard from the previous panel.

What's available is not enough, so, yes, there should be more. On the other hand, I think that what we have can be better coordinated.

Mr. BARTLETT. Okay.

Ms. Enders?

Ms. ENDERS. I agree that funding is the primary issue.

I'd like to elaborate just a little bit. We heard the previous panel say that lack of information, stigma and cost were the three issues and that lack of information was the prime one.

I think that we have to look at both low-cost and high-cost items.

For those low-cost items, the ranking is lack of information, stigma, and cost. But as the cost increases, the cost barriers become more significant. I think that when we're looking at it from that point of view, we need to integrate that information and look at a spectrum of consumers.

At one end of that spectrum, there is the disabled individual who has money or who has access to credit. They need information, but

they can support the purchase of the products they need. That's one end of the spectrum.

At the other end of the spectrum is the disabled individual, themselves, who knows exactly what they need. They don't have a lot of need for service intervention—what they need is money.

If we don't build a system that has both of those ends in it, we're going to have real problems. We're going to be providing services for people who don't need it, and we're going to be not allowing the consumer to really be a part and to use their life experience in what they need to come into the system.

Some people are going to need 100 percent subsidization. I think when we look at a woman paying $1,400 as her 20 percent match on a $7,000 wheelchair, that just makes your heart break.

I think that the cost and a range of participation in consumers, all the way from total, 100 percent subsidy for their products to loan guarantee options at the other end—we've got to look at a whole range of consumer payment options.

I think that the second most important reason why the system isn't working, and what we could do to make it work, is to recognize the ongoing need for technological support. All of our payment systems and our support systems have been based on graduation, closure, aging out. Someplace, they end.

Technology needs do not end. If you need one powered wheelchair, that little boy is going to need another powered wheelchair later. He's going to need adapted vehicles when he gets older. He'll need another communication aid.

That's an ongoing need, and that's a very new concept in how we provide services to people with disabilities. It fits very much into the independent living model of supportive services.

The other part of the ongoing part is the integrated nature. Technology must be integrated into the rest of supportive services. It fits very closely with the personal assistance of a personal care attendant or a reader or an interpreter service, as we've been seeing this morning.

These are people assistants—people helping other people, and technology helping people. It's part of the same package of supportive services. And it's a real mistake to segregate them apart.

People don't look for information about which widget they can buy. They're looking for information about how they can be functional in society. So, if the only information we provide an individual with is the information about how to buy a widget, we're doing them a disservice.

Maybe what they really needed was somebody to read to them, rather than a reading machine. Or they needed a set of those options, and our resource allocation policies right now are making it almost impossible to combine the kind of services and technological support that are necessary.

You either get personal assistance or you get a technological piece of assistance. We're already learning to write cost benefit arguments that say, "If we provide this technology, the person will use this much less attendant care service" rather than saying, "This much attendant care service and this much technology support and this much environmental modification together provide a reasonable package of support in the community."

I think that's important. And the last part that relates back to funding is the quality assurance issue. I think that we have to provide confidence in the decision makers who are purchasing equipment that they're getting their money's worth, whether it be a third-party funding source or the consumer.

We need to be sure that when you're buying something, be it public or private funds, that you're expending money wisely. Right now, our quality assurance mechanisms are not in place very well. They're geared to exclusion rather than to inclusion. I think that standards certification, the right kinds of personnel—those kinds of issues are going to have to be addressed.

Realistically, why we think it's so important that they be addressed is because we're not going to be able to work with especially the medical system in providing money out of health care oriented systems until we can show them that they're getting quality for their money.

So this is an important issue up front, if we're going to look at broadening resource allocations.

Mr. BARTLETT. That then helps me to pose my next question, which I'll let you start with. We'll then move to the other two.

If funding for the consumer is either the number one need, or at least in the top three, how would you, if you were in our shoes, choose to target that funding in terms of the allocation of resources?

Ms. ENDERS. This may be a cop-out, but I think that I'd start in studying some of the issues involved and trying to get some of the players together in this ballgame.

This cannot be simply solved by just looking at education and vocational things. Health care, whether we like it or not, is a really important factor in all technology funding.

I think that those players need to start talking to each other.

One comment that we've heard from some of the States is, "Why should we expect the States to be able to do this, if the Federal Government can't?" I think there needs to be more coordination starting with some Federal leadership in that coordination.

Mr. BARTLETT. Dr. Boardman?

Dr. BOARDMAN. Thank you.

In terms of targeting, I think that I'm with Alexandra. I'm too much of a scientist to say anything other than needs assessment.

There were many areas when we were doing our review where we simply didn't have the data that we needed. We couldn't say what the needs were in minority communities, for Spanish language services, for rural services, not in the way that we really wanted to be able to.

That sort of needs assessment is important. That feeds into the second point that I would suggest—which is that there are probably very significant regional variations in how you would want to target. There's no guarantee of what you need for services in Montana, or in Texas, or in New York.

In fact, it's very easy, having been a caregiver before I was an analyst, to visualize that what you would want for services in an urban area with a high foreign-language speaking population would be a very different pattern than what you would want in an extremely rural area, where you might want to depend on very cre-

ative alternatives in terms of information delivery and transport, rather than focusing on delivery of high-intensity care.

The third thing that I would suggest in terms of targeting funding is that you shouldn't simply think in terms of Federal funds, but in terms of how we can force other sectors to participate also, in fairly straightforward ways.

If we're talking about trying to get technology to get people employed, we should consider what information we're providing to make it easy for employers to hire these people. Employers should have access to the sort of information that will allow them to adapt their environment so that we can get people into those workplaces and so that we can convince people that these people are reasonable job hires.

We should look at the private insurance system and see what it is doing to support this sort of funding, so that it's not simply the Federal Government.

The fact of the matter is that the population that you're talking about is disproportionately low-income and disproportionately unemployed, probably more than any other population in the country. A significant part of the burden is going to come onto the Federal programs in terms of health care, support and income support.

Mr. BARTLETT. Mr. Weisman?

Mr. WEISMAN. There is a real need for providing funding for people with disabilities to buy devices, whether they are commercially available devices or not. That's certainly a real problem.

On the other hand, there are mechanisms that exist now to provide some types like that. Medical model, Medicaid, State agencies, voc rehab in terms of vocational programs, the educational model in terms of special education. Those things—a lot of time they fill the need, and many times they don't. A lot of times they aren't enough.

On the other hand, I think that whatever legislation you come up with needs to look at those things. As important as it is to expand those things, you have to full the gaps—find those places where people need devices or technology but can't get it in the traditional model, or someplace where there is money there now. That's very, very important.

The expanding of the present funding mechanisms will certainly help, but I think that developing those service programs that know about the technology and can deliver not just the product but the evaluation and the training for and the maintenance of that equipment—that's very important as well.

Mr. BARTLETT. Thank you.

Thank you, Mr. Chairman.

Mr. OWENS. I'd like to thank all of you very much for your testimony.

Our next panel is Dr. Alan Cavalier, Association for Retarded Citizens, Arlington, Texas; Dr. John DeWitt, Evaluations Coordinator, National Technology Center, American Foundation for the Blind, in New York City; Ms. Mary Ann Carrol, United Cerebral Palsy, New York City; and Mr. Roland Hahn, Director of the Central Pennsylvania Special Education Resource Center.

While you're taking your seats, we'll take a three-minute break. Recess for three minutes.

[Recess.]

Mr. OWENS. The meeting will please come to order.

We'll begin with Dr. Alan Cavalier.

STATEMENT OF DR. ALAN CAVALIER, ASSOCIATION FOR RETARDED CITIZENS, ARLINGTON, TX

Dr. CAVALIER. Thank you.

We appreciate the conduct of these hearings on such an important set of issues. I appreciate the opportunity to present this testimony to you.

I'm speaking on behalf of the Association for Retarded Citizens of the United States, headquartered in Arlington, Texas. I'm speaking on behalf of people who primarily have cognitive impairments—those with mental retardation.

Many children and adults with mental retardation or other cognitive impairments can be more independent in their activities of daily living. They can learn more skills, be made more employable, and be made more productive when employed. They can be integrated into the mainstream of society through appropriate assistive devices and related services.

Children and adults with retardation are not deriving those benefits now from today's advanced technology. Primarily, the devices that exist that can focus on their important needs are not accessible to them. Many of those needs do not have any products or services that are available.

I'd like to direct my comments today on the availability and accessibility of assistive devices for people with cognitive impairments.

Before getting into the rest of my testimony, I'd like to show you a brief videotape that focuses on some of those issues that I'll be bringing up—the adaptation of existing technology for people with cognitive impairments.

[Videotape shown.]

Dr. CAVALIER. Shirley's system was made up of primarily off-the-shelf components. One of the reasons for 42 years that she was left to a life of inactivity and one of low expectations was that people pretty much believed that she could not do anything for herself and basically had no preferences or desires. These are the hallmarks of a dehumanized life. There was not information awareness by her parents and the caregivers and the professionals who oversaw them as to what was available.

It gets at a lot of the factors that you've been focusing on, Mr. Owens and Mr. Bartlett, particularly in your opening statements. You talked about communications aids and environmental control systems that are now available.

Shirley's system now provides speech translation for her, so that the more unintelligible sounds will now be translated into complete spoken sentences in more normalized English. There's another interface where someone who's more handicapped than Shirley can activate the speech or the environmental control by just moving their eyes. That's very much in the experimental stage.

The problem is, while we're doing developments of that, we have to give the information and those services to our local chapters.

ARC is comprised of over 1,300 local chapters around the country. Shirley is very representative of what's happening to people who are severely handicapped, and other applications for those who are mildly handicapped. There is an information route and there's a services route.

Some of the other factors that lead to the inaccessibility of this off-the-shelf technology that could have been used four or five years ago—part of the reason that they're inaccessible, even though they are available, is that we also had not taken the time to develop training strategies. Strategies to train someone how to use a device.

It's easy to focus too much on the devices themselves. As you saw in Tommy's device, they're fairly complicated interfaces. Once a device is available, systematic training procedures are needed to get optimal use for them.

That gets into personnel preparation issues. This is one of the things that I'd like to emphasize very strongly for you to include in your preparation. This personnel preparation—there are not service providers out there that are well-versed in the technology that is currently available, and that leads into various institutional training programs that we have in universities.

I know of none, not even in the area of communication—speech pathology—even a year ago that required training or expertise in augmentative communication aids, despite the great number of them on the market now. Although in the local service provision, the speech therapist or the communications disorders therapist is looked upon as the expert, we have a system where there is not a lot of training yet being delivered. You end up having to learn by the seat of your pants, out in the front lines.

An earlier panel talked about how many times the users have a heavy personal motivation to get into the technology and then end up training those professionals in their local communities. Our local chapters are finding that the service systems aren't aware of what's available. When the clients are made aware, in many cases, there are no professionals who could provide guidance.

Rather than doing a comparative analysis on what's the best technology, if the technology is appropriate—which in many cases it's not—it's very difficult to find guidance on that. Consequently, you may be purchasing the only one that you know of, or the only one that you can get your hands on.

As you were focusing on earlier, Mr. Bartlett, there's no easy access to a fitting room, if you will. The service system that's available in this country is very fragmented, as we've heard already. Consequently, there are very few places where someone can go out and be an informed consumer, when they are a consumer of assistive devices.

I'd like to focus now on the actual design of the devices. Many of the devices that are currently available are not accessible for the reasons that I've said. But many devices that could be available are not. When you're talking about people with cognitive impairments—there are a lot of reasons for that.

A few of them are worth focusing on right here. The field was first introduced to technology for physical impairments. It turns out that the cognitive demands that devices place on users are uni-

form. If anyone can remember the first time they operated their office computer—the cognitive demands then were pretty staggering. In fact, many of the assistive devices now place too great cognitive demands on the users. They're either very laborious or very complicated to use.

In some areas, devices don't exist where serious needs are. I'll give you another example to an application that was focusing specifically on people with cognitive impairments.

We're currently developing a device that we call a bladder sensor—an ultrasonic bladder sensor. It's a small, non-invasive ultrasonic device, almost like a Walkman-size device right now, that you would clip on your belt, which is attached to a small sensor, a little wafer that's positioned on your abdomen.

The basic need that we were addressing was a need that exists in a large number of people who are retarded, so we're trying to address them as our primary focal group. That is that many of them, despite the best behavioral teaching approaches, do not learn to be successfully independent in toileting. They're not toilet trained.

And adults that are not toilet trained, as well as children who are not, suffer a great stigma and are also restricted from vocational and educational programs. It's basically a gateway that they cannot pass, even though they might be getting onto higher order cognitive skills.

So this device was focusing basically on that need to provide some assistance in the one cognitive area that seems to be the flaw in the toilet training program. That's recognizing the association between the subtle internal sensations of a full bladder and the toilet training steps that we all execute after we recognize that.

That association is very difficult for some of our people to learn, and in fact there's very little we can do for that since the stimulus is internal. Our teachers can't color code it or draw attention to it on a blackboard. There's just no way of getting at it.

The bladder sensor that we're near finishing in development basically just looks at the bladder all day long with ultrasound. The unit is constantly processing those signals, and when a certain level of fullness is reached, it provides an external signal to the user. It could be a subtle tone through a hearing aid, a little LED on the glasses, or the device itself might vibrate, for subtle tactile pressure.

If we had designed that only for people with retardation, it probably would have too small a market to be viable in the marketplace, as so many other products are collecting dust on engineers' shelves. It basically could not be supported by a company that needs to turn a small profit to stay in existence.

So, what in fact was included was a strong interdisciplinary effort, looking at the needs of other handicapping conditions, so that the design from its inception was more flexible. It includes a great deal of individualization. You can set parameters on the device that allow it to serve a number of handicapping conditions.

It turns out that while there may be 150,000 to 200,000 people who are retarded who have a need for the device, when you look at people with advanced age or advanced diabetes, people with quadriplegia, you find that those numbers total over 6 million Americans

who have a need so that the device could facilitate their independence in toileting.

The major point that I would like to make is that not all these devices are currently available. But if designed flexibly enough, they can serve functional needs that cut across traditional labels of disability, and therefore will be more viable in the marketplace.

One other thing dealing with the research that feeds into the service delivery systems. Right now, the research times lines and dollar resources that are committed to research and development methods are based on an older model in which research was done on curriculum materials. This doesn't fit very well in terms of making advances that can serve a variety of handicapping conditions.

Typically, lots of the Federal projects are funded on 18 months for research and development. It turns out that there's not a lot of time to do research on an interdisciplinary fashion—which is a whole new type of research—before you do development. Rather than answering questions through research as to whether the approach should be electrical impedance or ultrasound, to have the best device that's the most durable and effective, you end up often taking a best guess, since you need to get into the development efforts.

Of course, the errors you commit can get multiplied as you go down. If you could include in your thinking a reconsideration of how research and development efforts could feed into the availability of products for people who are cognitively impaired, or who have other handicapping conditions, I feel that the advances will be more pervasive.

Thank you.

[The prepared statement of Dr. Al Cavalier follows:]

STATEMENT OF AL CAVALIER, PH.D., DIRECTOR, THE BIOENGINEERING PROGRAM, DEPARTMENT OF RESEARCH AND PROGRAM SERVICES, ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES

Children and adults with mental retardation or other cognitive impairments can be more independent in activities of daily living, can learn more in school, can be more employable and more productive when employed, and can obtain more satisfaction and enjoyment in their leisure when provided appropriate assistive devices and strategies for their optimal use. Children and adults with mental retardation or other cognitive impairments are not deriving these benefits from the nation's advanced technology. Products responsive to many of their important needs are not available. For those needs for which products are available, they are not accessible.

The sophisticated use of tools distinguishes us from all other beings in the world. In this context, tools can be looked upon as extensions of ourselves to augment our abilities and compensate for our limitations. Today's technology represents the most advanced and powerful set of tools yet devised. We can transmit our voices instantly across the ocean by pushing a few buttons, regulate the surrounding temperature by turning a dial, and cook a whole meal in a matter of minutes by setting a few controls. All such augmentations and compensations are adaptations to serve our needs, and while most of us take for granted these prostheses, the net result is a dramatic increase in our productivity, efficiency, and leisure. The applications of technology, however, have thus far discriminated against a large number of American citizens. Our technological advances have not been designed with sufficient creativity and flexibility to incorporate the needs of many people who are mentally retarded. Society has yet to produce assistive devices or incorporate assistive features for people who are mentally retarded. It is the belief of the Association for Retarded Citizens of the United States that these advances will not occur without strong leadership from our federal government.

To date, the private sector has been primarily responsible for the few innovations in devices, techniques, and services that are currently available. The Bioengineering Program of the Association for Retarded Citizens was initiated in 1982 to explore the contributions of advanced technology to serving the needs of people who are mentally retarded. The Program has three major purposes: a) to modify existing devices and to develop new devices that are responsive to the needs of people who have cognitive impairments, b) to research training procedures and techniques that improve the use of assistive devices; and c) to improve the delivery of services that include technology assistance.

In conducting its activities, the Bioengineering Program makes use of a nationwide network of over 1,300 state and local ARC chapters, the majority of which are service providing agencies in their local communities. Based on this chapter structure and over 160,000 members, the ARC is the largest voluntary organization in the country devoted exclusively to the welfare of children and adults with developmental disabilities and their families.

EXAMPLES OF IMPROVING THE AVAILABILITY OF ASSISTIVE DEVICES FOR PEOPLE WITH COGNITIVE IMPAIRMENTS

Independence in toileting

In attempts to normalize the lives of children and adults with mental retardation, much energy has been devoted to teaching these individuals to function independently in society. The problem of incontinence often thwarts the best of these efforts. Successful toilet training depends on the learner recognizing the senation of a full bladder and then associating that feeling with the toileting routine. For many people with severe and profound mental retardation, this connection between internal state and external behavior is difficult to establish. While toilet training programs are quite effective in teaching some people that routine, these programs typically presuppose that all people are already cognitively aware of those sensations. However, children and adults who are severely cognitively impaired have difficulty detecting these subtle and obscure signals.

Incontinence typically results in a negative stigma for the person, reduced positive interaction with other people, unsanitary living conditions, excessive laundry expenses, and increased custodial attention by caregivers. Because of incontinence, individuals are often actually denied participation in a variety of educational, vocational, and social programs—all of which are critical experiences necessary for their developmental growth and integration into community life.

As a consequence, the ARC Bioengineering Program has been developing an assistive device that allows individuals and caregivers to recognize when the bladder is sufficiently full. The bladder sensor uses ultrasound to monitor the volume of urine in a person's bladder throughout the course of a day and then provides a subtle signal when a specified level of fullness is reached. To accommodate individual needs, the signal can be an auditory, visual, or tactile cue. With the device, individuals can be taught to take responsibility for recognizing the need to urinate, first by relying on the device and then by relying on the internal feeling that comes to be associated with the signal from the device. At the same time that people are being trained to use the device, they should also be learning toileting skills so that they will know the proper routine once they recognize the need to urinate.

The device consists of a small sensor positioned on the lower abdomen that is connected to a "walkman"-sized unit in which all the processing logic is located. When the logic unit determines that the bladder has reached the level of fullness specified for an individual's needs, a signal is given to the individual wearing the sensor and, if desired, transmitted remotely to a parent, teacher, or nurse.

The development of this device is funded in part by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education and involves a collaboration with the ARC, the University of Tennessee Medical School, NASA's Technology Utilization Program, and local ARC chapters.

While the device was designed from the outset for the needs of people with mental retardation, sufficient flexibility in adjusting different paramerters was also intentionally designed into the device to permit it to be responsive to the largest consumer base possible. As such, the device can also provide increased independence for people who have permanently lost the ability to control their bladders for medical reasons, such as spina bifida, quadriplegia, diabetes, cerebral palsy, and advanced age. An initial market analysis estimates that there are over five million American citizens that could benefit from such an aid. We believe that not only can assistive devices be designed to accommodate the needs of people who are cognitive-

ly impaired, but they also can be designed flexibily to address a much larger population and thereby survive in the marketplace.

Improvements in cognition

While most instructional software packages are based on general educational principles, few are precise translation of well-proven educational procedures. Exact translations are difficult to achieve because they require complex programming: detailed instructions and examples, varying levels of difficulty, motivating rewards, corrective feedback, and sophisticated analysis to individualize instruction to each student. It is important to note that what is being referred to is the transfer of an entire instructional procedure, not just a learning task.

Cognitive process deficiencies represent a critical problem for people with mental retardation and learning disabilities. Many reserchers have studied how people process information and have identified ways to remediate processing problems. Unfortunately, the procedures are complex and very laborious and, consequently, are not used by teachers in our nation's schools. We believe these conditions justified attempting to automate the remedial procedures on the personal computers typically found in the schools. This was an important focus, since if it were successful it would achieve gains in the fundamental cognitive skills that underlie all other higher order areas such as reading and mathematics, thereby producing benefits in all of those areas.

With this in mind, the ARC Bioengineering Program, with support from the Office of Special Education Programs of the U.S. Department of Education, designed, developed, and evaluated software to assess the cognitive needs of students with mental retardation or servere learning disabilities and then to remediate them.

The software that was developed incorporates assessment and remedial components along with sophisticated ongoing analyses and opportunities to play an exciting video game. Individual cognitive strategies are trained separately at first. Then students are trained to chain them together. The computer always starts by demonstrating what it wants a student to do and then gradually fades the amount of assistance it provides until the student is performing independently. The software incorporates animated graphics as well as written and spoken instructions and comments. It also responds to inputs other than they keyboard (lightpens and joysticks). These accommdate individual needs and allow the students to interact with the system without taking their eyes from the screen.

Extensive field testing in public schools showed that not only did the software improve the cognitive skills of students who were mentally retarded or learning disabled, but it also refined the skills of students who were not disabled.

We believe today's technology provides the most powerful tools to directly address the congitive needs of children and adults with mental retardation or other cognitive impariments.

Freedom of choice and expression

Persons with profound mental retardation and severe physical impairments often are bed or wheelchair-bound with very limited control over even gross motor movements and often are capable of making only unintelligible sounds—truly a difficult challenge for caregivers and teachers. They are usually totally dependent on others to discern their basic needs such as thirst, hunger, or toileting, and to make choices for them that agree with their desires such as turning on the TV or rolling over. If their needs are not discerned by others, their needs are not met. Often these individuals are denied by their disabilities—and society's response (or lack of response) to them—the social interactions, opportunities for productivity, and personal fufillment to which everyone is entitled. It is too easy for other people to come to believe they have no preferences and no desires. Parents and other caregivers are also severely impacted by the multiple handicaps in that they are needed to provide extensive care and attention.

People with severe multiple handicaps often appear passive to caregivers, who react by offering few opportunities for active involvement in decision making. Such circumstances typically result in extreme frustration, increased passivity, and helplessness in people with these handicaps. This ironically reinforces the dependency and creates a cycle of diminished expectations. What is needed is a new arrangement of the environment that allows "dependent" people to exercise independent control over various aspects of it. Increased self-esteem and independence for the disabled individual is the result, along with altered perceptions on the part of caregivers.

The ARC Bioengineering Program believed assistive technology might hold the key to such a reversal. The assistive device developed to address this situation was an off-the-shelf computer system with voice recognition capabilities that was linked

through newly-developed software and a variety of interfaces to such items as TVs, radios, electric fans, vibration massage pads, and videocassette recorders. While environmental control systems have been used by persons with physical handicaps who are not cognitively impaired, it had never been determined whether someone with profound mental handicaps and severe physical impairments could learn to purposively use such technology or if the benefits of such use would be substantial. The basic intent was to configure a computer-based assistive device to intervene for the subject at his/her choosing to provide some freedom of choice and control over significant aspects of his/her environment.

The subject selected for this investigation was 42 years old, possessed no self-help skills, was completely dependent on others for the fulfillment of all her needs, had almost totally unintelligible vocalizations, and was confined to a bed or gurney chair all of her waking hours—a person representative of most of those who are waiting to be released from institutions. The basic questions were: Could she understand the concept of "control" after never having experienced it in her life and would she use it constructively?

The system was activiated entirely by voice. The woman who was disabled needed only to make consistent sounds—they did not have to be real words—in order to turn the appliances on and off at her choosing. Results showed that the woman not only learned the cause and effect relationship between making a sound and activating a device, but she also learned to discriminate among the devices and select only those she cared to operate and only at the times she cared to operate them. She also became much more animated and expressive.

The woman expressed obvious pleasure while using her system and appeared to take pride in demonstrating it to others. Videotapes captured her laughing and exclaiming with delight when she realized her impact on her surroundings by operating the device. She also expressed displeasure when the system was temporarily diabled. She had distinct preferences among the applicances and seemed at times to turn them on and off the sheer pleasure of being in control.

The woman's caregivers were surprised to observe her newly revealed skills, and began to behave differently themselves. They interacted with her more frequently and encouraged her participation in decisions about her daily routine.

This research shows what is possible with commonly-available computers and peripherals. It demonstrates that people with profound mental retardation, who typically receive the most minimal of services and are the last to be considered for more normalized living routines, can begin to exercise the basic fundamental rights of freedom of choice and expression through advanced technology and skilled training procedures. Hidden capabilities can be unmasked and new skills developed. As the technology continues to be refined and extended, it can also offer to parents teachers, and therapists optimism that more normalized and rewarding lifestyles are indeed possible for people with severe cognitive impairment.

EXAMPLES OF IMPROVING THE ACCESSIBILITY OF ASSISTIVE DEVICES FOR PEOPLE WITH COGNITIVE IMPAIRMENTS

Integrating technology assistance into service delivery

In conjunction with the ARC, the University of Texas at Arlington has been conducting a three-year effort to design, implement, and evaluate a model strategy for integrating technology assistance into an exisitng developmental disabilities service delivery system in a large urban community. As part of this effort, the ARC operates a telecommunications network comprised of an electronic mail and bulletin board system to provide information sharing among service providers and consumers and a computerized database of resources on the application of technology for people who are disabled.

Results of these efforts show that a critical factor in an effective community service delivery system that includes technology assistance is the delivery of the services by adequately prepared professionals and paraprofessionals. Easy access to a pool of information is not enough; service providers must be trained to assess a person who is cognitively impaired for the appropriateness of technology assistance, to prescribe the appropriate assistive device, to teach the proper use of the device, and to evaluate its continued appropriateness. A second critical factor is the provision of follow-up support after a consumer has purchased and been using the assistive device for some time. Too often, a consumer is totally on his or her own. A third critical factor is the provision of sustained interaction between consumer and device prior to purchase, e.g., centralized sites where an extensive collection of assistive devices can be "tried on" under skilled supervision and provided on a loan basis for a period of time sufficient to determine the appropriateness of the consumer/device match-up.

Strategies more than devices

For two years, the ARC assisted the American Speech-Language-Hearing Association (ASHA) in improving the use of augmentative communication aids in the nation's schools by children having little or no intelligible speech. Communication aids range widely in complexity, design, and cost. This study identified 11 exemplary communication programs in the nation. These programs were analyzed to determine why they are successful and how they have dealt with obstacles to providing appropriate communication services. For people with cognitive impairments, once again, a critical factor was shown to be the assessment of their abilities and of the appropriateness of technology assistance by skilled clinicians.

It is important to note that, as in the case of many of the rehabilitation engineers who helped to pioneer the field of rehabilitation technology, many of the early leaders in augmentative communication—who still exert strong influence over the field—have had limited experience with children and adults who are cognitively impaired, are unfamiliar with the skills that they have been shown to achieve, and hold dismal beliefs about their ability to benefit from communication aids. As a result, most communication aids were not designed with interfaces that permit access by these individuals. More creative reseachers and clinicians have shown that not only do such aids significantly enhance the ability of children who are cognitively-impaired to speak, but they also represent powerful new tools to teach them language and its functions, thereby permitting them to participate fully in the educational process and beyond.

RECOMMENDATIONS

(a) Technology assistance can significantly improve the independence, education, productivity, leisure, and integration of citizens who are cognitively impaired. Such assistance must be integrated throughout all of those areas of a person's functioning and throughout his or her lifespan.

(b) Rather than coordinate a variety of technology services that already exist in fragmented fashion around the country, the federal government must assist in the creation of those services. They do not exist.

(c) There is no comparison between today's technology assistance and anything we have witnessed in the past. We should not be constrained to adopt existing service delivery models for this new enterprise. We should not rely on old solutions to such novel problems. New systemic design is needed.

(d) Very few assistive devices that are responsive to the important needs of people who are cognitively impaired are currently available in the market place. Research and development of new assistive devices that focus on such needs and that are more flexibly designed should be supported.

(e) Of those assistive devices that are available for people who are cognitively impaired, most of them are not accessible due to designs that did not take into account cognitive needs, training strategies that have not been developed to teach their use, and practitioners who are ill prepared to assess and train. Personnel preparation, both preservice and in-service, must be a major component of a nationwide service delivery system.

(f) Research and development efforts in this new area typically are more expensive and require more time than other research projects. To realize the powerful benefits of technology assistance, we must commit larger budgets and longer timelines for federal projects in this area.

(g) There is a prevailing belief among many of the leaders in the field of assistive technology that people with mental retardation or other cognitive impairments are not appropriate consumers of assistive technology. They have had limited or not experience in applying technology assistance to such individuals. They are prisoners of the past whose self-limiting beliefs create self-fulfilling prophecies. People with mental retardation or other cognitive impairments should be named as "traditionally underrepresented groups" with regard to technology assistance; otherwise it will become a further means of discrimination against these groups.

(h) Accurate information on the nature and extent of the existing and future market for assistive devices and services has a critical role in the definition of research and development agendas and ultimately the responsiveness of the service delivery system. Demographic studies should be supported, with assurances that people who are cognitively-impaired are not excluded.

(i) Research on training strategies and procedures to teach optimal use of assistive devices is extremely important for people with cognitive impairment, and should be supported by the federal government.

(j) Technology assistance assists the family of people wo are disabled as much as, and sometimes more than, the individuals who are disabled. These profound effects must not be overlooked or underestimated.

(k) Consumers in many cases need financial assistance in purchasing assistive devices and related support services.

A CONCLUDING PERSPECTIVE

We are at a very primitive stage in the history of technology assistance. Disabilities need not be handicaps to a person's independence, learning, productivity, leisure, or integration. In too many cases at this point in our history, they are. I have a severe disability. In more primitive times, my independence, my productivity, my enjoyment of life, would have been severely restricted because of this disability. I would have been severely handicapped. Because of an assistive device that everyone long ago has taken for granted, which has become "invisible" because it is so commonplace, this is not the case. If you took away my eyeglasses and then observed how I behaved through the course of a day, you would have no doubt that I was handicapped. Imagine my chances of survival in more primitive times! With the technology of eyeglasses and with its associated service delivery system, I no longer give any thought to my disability. I don't need anyaone to do anything for me, and my potential, which was so low without the technology, is now much greater. I am not handicapped.

For children and adults with mental retardation, we are back in those primitive times. With appropriate technology assistance, we can keep their disabilities from becoming handicaps; we can free them to be more independent and productive. Today's technology offers unprecedented opportunities for them to avhieve their full potential and enter fully into the mainstream of life. When we are in a less primitive time than now, their assistive devices will draw no more attention and be no less accesible than eyeglasses are today. We can begin to make those strides today.

Thank you.

Mr. OWENS. Thank you.

Mr. DeWitt?

STATEMENT OF MR. JOHN DeWITT, EVALUATIONS COORDINATOR, NATIONAL TECHNOLOGY CENTER, AMERICAN FOUNDATION FOR THE BLIND, NEW YORK CITY

[Computer speech.]

Mr. DEWITT. That's by way of a small introduction.

That's a small talking computer that I use when I travel, to help me take notes and to sometimes talk to you.

I'm John DeWitt, as you know, from the American Foundation for the Blind, where I am evaluations coordinator of our National Technology Center.

The purpose of the National Technology Center is to help to develop, evaluate and provide information dissemination about adaptive technology devices that will benefit persons who are blind or severely visually impaired.

One of the benefits of being this late on the agenda is that we have the chance to hear what everyone else has said, and in some cases not to duplicate it.

Mr. OWENS. Thank you for waiting so patiently.

Mr. DEWITT. Oh, my pleasure, really.

Also I can synthesize what I hear other people saying.

Rather than reading my written testimony, which of course you have, as well as many of the members of the audience here, I'd rather try to punctuate, and underscore, some of the things that I feel are important here in the draft language of the Jeffords-Bartlett bill and some things that I've been reading in the Kerry-Tech

bill and the proposed language for the Harkin bill in the Senate, and so on.

My overall impression is that we need—and I think this is borne out by what Barbara Boardman said, and others—to take a really comprehensive look at how technology can be appropriately designed to serve the needs of the consumer. This needs coordination. I think that's the single most important word that I could use.

For example, we have some problems between States. I know of a young woman living in one State, getting some assistance there for her education, particularly education to be job-ready, who was given a closed circuit television system, a product which magnifies an image on television monitor—a print image. She was sent to learn computer programming and computer use, which she did at a training center, one of the very few around the country which can serve blind or visually impaired people.

When she got all through, she was job-ready to handle a job which involved the use of a computer, and she had her CCTV, which was not hooked up to a computer.

Now, she moved to another State, in order to get a job. While she was in the first State, the other State closed out her case, without any other assistive or adaptive device. She needed another product on the job, and she couldn't afford it herself. She had difficulty in getting the system to help her to get it. Only because of the ingenuity of a rehab counselor in the State where she got the job was she able to finally have her case opened in that State. Perhaps this was a little bit unorthodox, and finally, after a year's wait, she got the equipment which she needed.

Fortunately, this moves with her, as she has upward mobility, either within the place where she now works, or in the future with another employer.

A situation where a person again falls through the cracks—and this perhaps emphasizes the funding problem.

In a midwestern State, a woman employed in a State office is hired under a special handicapped program. She's hired as a writer of newsletters and publicity releases. She earns less than professionals at the same level of job—which is another issue altogether.

All her colleagues have a computer on which they do their writing. She asks for a computer and is willing to buy the adaptive peripheral—the device which would allow her to use synthetic speech with the computer—and the employer said no. It's too expensive.

The computer is too expensive, not to mention the peripheral. She was willing to pay for that peripheral. But she went to try to find the loan. Well, banks don't like normally to give loans for computers—it's hard for them to repossess them and have much value left. She went to an association which has some low-interest loan programs. They don't fund the computer, they only fund the adaptive device.

Voc Rehab wouldn't do it, because she has a job. Unless she was threatened with losing her job, they couldn't intercede. There was a problem of attitude on the part of the employer, and the problem of too much money to buy both the computer and the peripheral, and not enough money in her savings accounts. She's stuck.

She cannot be as productive as she knows she can be, nor is she even as productive as she could be for her employer.

These are only two very brief examples of the kind of thing that happens with uncoordinated technology assistance within States or between States.

I think that Dr. Boardman mentioned that there is a great disparity between the delivery system in various States. I think that is a problem that must be addressed.

In the Jeffords-Bartlett bill here, there's a lot of talk about planning coordination on the State level, but not very much between States. It seems to me that has to be addressed.

That problem is also going to plague us if we don't address it in terms of information dissemination and referral. What Alexandra Enders was discussing about Abledata comes home to roost in all this information area.

We've got a lot of people collecting information, and a lot of people doing redundant work. It would be a pity, I think, for each State to develop its own information dissemination program. They would be collecting information that's being collected by every other State. We don't need to do that.

There should be at the very least regional centers that collect information from each State and from the national level, or perhaps there should be disability specific centers.

All of those might feed into a national center, but we do run into the problem of access to the information. As Barbara said, we have hardware and software, but we need the liveware. At our National Technology Center, we receive a dozen phone calls a day from individuals who are looking for solutions.

My goodness, seven minutes goes by fast when you're having fun. [Laughter.]

They are looking for someone to talk to. If they had on-line access to a database, most of them would still not find the answers to their questions. They need to talk about what tasks they're trying to perform, and what kinds of solutions would fit those tasks, based upon a person who has experience with this.

We need to have people talking to people.

There are really severe problems in accurate data collection about the demographics. We need to foster better information from a population basis about people with disabilities, and not rely on programmatic information, such as who is in the educational system and who in the VR system.

We need to look at the body of the population that has disabilities, and then from them look at those who might benefit from technology.

I'm sorry my time has run out. I have a lot more to say, and I hope that perhaps with staff or the rest of you, we'll be able to do that as time runs along.

[The prepared statement of John C. DeWitt follows:]

STATEMENT OF

THE AMERICAN FOUNDATION FOR THE BLIND

by

John C. De Witt
Evaluations Coordinator
National Technology Center

Before the Subcommittee on Select Education, U.S. House Committee on Education and Labor, 100th Congress, Second Session, May 10, 1988 regarding

Bridging the Communications Gap Through Technology for Blind and Visually Impaired People

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STATEMENT OF THE AMERICAN FOUNDATION FOR THE BLIND

by

John C. De Witt

Good Morning Mr. Chairman and members of the Subcommittee.

My name is John De Witt. I am the Evaluations Coordinator for the National Technology Center of the American Foundation for the Blind.

The American Foundation for the Blind (AFB), founded in 1921 through the inspiration of Helen Keller, is a national research and consulting organization in the field of blindness and visual impairment. The National Technology Center was officially established in 1986 to develop, evaluate, and disseminate information about technology benefitting blind or visually impaired persons. One of the Center's many projects is the maintenance of a national user network database, which currently lists about nine hundred blind or visually impaired technology users, who have shared with us extensive information about their use of technology.

AFB is pleased for this opportunity to testify today concerning key elements which Congress should address in adaptive technology legislation. My oral remarks will summarize our written statement which will be submitted for the record. Of course, we will continue to be available to this Subcommittee's staff as you consider legislation in this area.

I. BENEFITS AND BARRIERS TO TECHNOLOGY FOR BLIND AND VISUALLY IMPAIRED PERSONS

Mr. Chairman, I am convinced that access to adaptive technology has significant impact on the employability of blind and visually impaired persons. As a person with a visual impairment, I am a user of adaptive technology myself, such as this portable Epson computer which has been modified for synthetic speech output. Greater access to information through technology, as well as the ability to more quickly and accurately communicate in written or electronic form with my colleagues, has made my work easier and more productive. From my experience at the Technology Center, I also know that many other blind or visually impaired people have similarly benefitted from technology. Among the 903 blind or visually impaired technology users currently listed in AFB's technology user's network, 82 percent are employed. By comparison, approximately 66 percent of this nation's blind and visually impaired working age population are either unemployed or are not in the labor force. Of the employed technology users in our network, 62 percent report that they use computers with speech, braille, or large print output, and 80 percent of these computer users further report that they use their equipment from 5 to 7 days a week. A detailed summary of our network statistics is attached to my written statement as Appendix A. Thus, it appears that use of adaptive technology impacts upon both the business and personal lives of our network participants.

Yet, we need to reach countless other persons with not only information about adaptive technology, but also the means to effectively utilize it in all aspects of life. Most blind and visually impaired people are poor. In a 1977 survey conducted by AFB for the National Library Service for the Blind and Physically Handicapped, approximately half of the households containing one or more users or potential users of braille and recorded library service reported household income below $5,000 before taxes. The 1976 Survey of Income and Education of the Census Bureau indicated that 19 percent of visually handicapped men and 33 percent of visually handicapped women lived in poverty, as compared to 7 percent and 10 percent for the population as a whole, respectively.

Thus, although adaptive technology does seem to benefit those who are lucky enough to have it, most blind people are not in an economic position to individually acquire this technology, absent third party financial assistance.

II. BASIC ASSUMPTIONS

Mr. Chairman, as you know, several pieces of adaptive technology assistance legislation have been introduced or are being circulated for comment as draft legislation prior to introduction. We at AFB have reviewed these bills and/or drafts, and find elements of each to be worthy of further study and consideration. We believe, however, that whatever legislation that is ultimately enacted into law is only the beginning of an

evolutionary process toward achieving sound public policy relative to how we meet the technology needs of persons with disabilities. The field of adaptive technology is in its infancy, and accordingly, we are still working out satisfactory answers to such questions as: What is the appropriate definition of technology? Who decides what devices and services are necessary? Who pays the bill, and how do we coordinate technology assistance with other programs (such as rehabilitation, education, and the aging service delivery system) both federally, and, within and among the states? How should we provide technology assistance to a person whose disability is not static at various stages of his/her life, to a person who is currently not a student or rehabilitation client, or to an older person whose independence with dignity would be enhanced through the use of appropriate technology assistance?

We should also keep in mind that, just as technology is not the panacea for every problem faced by a person with a disability, so too technology assistance legislation should not be expected to cure all of the ills of the rehabilitation, education, and aging systems.

Technology legislation must also be administratively and politically workable. By this I mean that the administrative structure created by adaptive technology legislation must not be overly complex. The definition of technology, as discussed more fully below, must be broad enough, but not too broad. The system must also take into account cost, and should be relied upon as

the "payer of last resort" when other systems cannot or will not provide assistance. Like it or not, cost will play a decisive factor in whether this legislation is enacted into law. The interests of blind and other persons with disabilities are not well served by drafting a statute whose breadth of coverage is exceeded only by its cost.

These and many other questions, Mr. Chairman, are complex (some would say mind boggling). I do believe, however, that together, we can develop an adaptive technology system which encompasses support for:

1. Development of new technologies;
2. Evaluation of existing products;
3. Information dissemination to consumers and professionals in accessible media;
4. Assessment of individuals' needs; and
5. Financial assistance (including cost of acquisition, training and maintenance).

We can make a beginning, Mr. Chairman, but keep in mind that we may have to install a new "logic board" tomorrow, as we learn more about this exciting new field of adaptive technology for persons with disabilities.

The remainder of our testimony will highlight some specific elements to be included in adaptive technology legislation.

III. DEFINITION OF TECHNOLOGY

"Adaptive technology devices and services means specialized devices and/or services designed to apply engineering methodologies or scientific principles to the amelioration of the effects of a person's functional limitations."

This suggested definition is not necessarily the ideal definition for adaptive technology, but is proposed as a starting point for further discussion. We believe that the definition of adaptive technology should relate to those specialized devices and/or services which reduce the impediments associated with a person's disability, and which enable such and individual to ideally perform all major life activities. Adaptive technology should not include medical equipment (such as prostheses or durable medical equipment as defined in HCFA's regulations), or routinely prescribed devices such as ordinary glasses or hearing aids. Rather, adaptive technology should relate to the devices and services which a person with a disability may need to overcome the deficits resulting from his/her disability. Thus, a talking glucose monitor which announces its readings would be adaptive technology, but an unmodified version of the same glucose monitor would not be. A talking computer system would be adaptive technology in that the computer is usable to a blind person through the incorporation of speech synthesis. By contrast, devices which are traditionally viewed as medical or cosmetic in nature, such as prostheses or durable medical equipment would not be adaptive technologies.

This approach to the definition of technology seems to us to be a reasonable compromise, since adaptive technology legislation should provide reimbursement for devices or services which are not otherwise reimbursed by third party health care payers or other service delivery systems. A limited definition of technology will also help to limit the cost of this legislation.

V. DATA COLLECTION AND AGENCY COORDINATION

The scarcity of reliable data concerning disability in this country is an ongoing problem, not only as it relates to adaptive technology policy, but also as it relates to disability programs and services generally. Manufacturers who must decide whether to commit resources to the development and marketing of adaptive technology always ask us about the number of potential customers for their products. Unfortunately, we do not have good answers to these questions, since we don't know much about the characteristics of persons with disabilities in this country. Accordingly, we urge the Subcommittee to examine this issue of data collection very carefully. Although this Subcommittee may not have jurisdiction relative to the National Center for Health Statistics or the Census Bureau, your support of funding for a post Census disability survey and increased research activity on disability by the NCHS would be very helpful.

Technology assistance has been incorporated in a patchwork fashion into a variety of federal and state programs. Any

adaptive technology legislation should also include a reporting mechanism (either on a regional or national basis) which would help to insure better coordination of effort between the federal government and the states. It is also important that comparative data relative to demographics of disability and approaches to adaptive technology assistance be collected on a state by state basis. Thus, if one state offers a tax deduction for the acquisition of technology, this information could be shared with other states which might want to replicate such a program.

V. AUTHORIZATION OF NATIONAL CENTERS

Mr. Chairman, we believe that any adaptive technology legislation should authorize funding for national technology research and demonstration centers. Such centers could provide valuable development, evaluation, and dissemination of information services to the disability community. Quite obviously, a person with a disability cannot turn to the latest issue of Consumer's Report to acquire objective, comparative data concerning various speech programs or synthesizers. It is important that the research and findings of these centers be distributed widely in accessible media. Simply providing information in printed form is unacceptable. In addition, although centers should have a specific disability focus in order to better address the unique needs of specific disability types, collaborative projects and sharing of information among centers

is essential. For example, developments in speech technology are of value not only to blind and visually impaired persons, but also to persons who are vocally impaired. Developments in "mouse" technology which permits easier direct access to the screen for people with motor impairments may also be adapted to permit direct braille access to the screen for a blind user.

VI. CONCLUSION

The American Foundation for the Blind will be happy to elaborate further on points raised in this testimony. Several other issues remain, however, for further discussion. For example, we believe that professional certification in the field of adaptive technology is necessary, but that development of appropriate standards will be a complex task. We believe that the technology needs of persons with disabilities can be accommodated over a lifetime through innovative approaches such as the recycling of devices, and that acquisitions of technology should not be limited to items contained on a state-approved procurement list.

Thank you for your interest in this important subject. I will be happy to try to answer any questions at this time.

Appendix A

AMERICAN FOUNDATION FOR THE BLIND - NATIONAL TECHNOLOGY CENTER

STATISTICS FOR VISUALLY IMPAIRED PEOPLE IN THE USER NETWORK DATABASE

TOTAL PERSONS REPORTING USE OF "ELECTRONIC" EQUIPMENT:	903 Responses	
GENDER:	903 Responses	
Male:	537	59%
Female:	366	41%
AGE:	893 Responses	
1-19:	14	2%
20-29:	92	10%
30-39:	365	41%
40-49:	192	22%
50-59:	140	16%
60-69:	68	8%
70-+:	22	2%
EDUCATION:	903 Responses	
Currently a Student:		
Yes:	82	9%
No:	821	91%
Highest Level Completed:	903 Responses	
Graduate Degree:	398	44%
Some Graduate Work:	63	7%
College Graduate:	213	24%
Some College:	147	16%
High School Graduate:	59	7%
Some High School:	12	1%
Grade School:	11	1%
EMPLOYMENT:	903 Responses	
Yes:	744	82%
No:	159	18%
COMPUTER USED:	898 Responses	
Yes:	554	62%
No:	344	38%
DAYS USED DURING WEEK:	554 Responses	
5-7 Days:	443	80%
1-4 Days:	111	20%
HAVE YOU RECEIVED TRAINING ON ANY EQUIPMENT:		
Yes:	387	43%
No:	516	57%

Mr. OWENS. Thank you.
Ms. Carrol?

STATEMENT OF MS. MARY ANN CARROL, UNITED CEREBRAL PALSY, NEW YORK CITY

Ms. CARROL. Yes. Good afternoon. I do appreciate the opportunity to speak to the subcommittee on this very important topic.

I'm the director of research and special projects of the United Cerebral Palsy of New York City, and I'm here today to testify on behalf of our national organization, United Cerebral Palsy Association.

Our local affiliates and our national organization are concerned with services—direct services—and advocacy and supportive services for people with cerebral palsy and other developmental disabilities, and their families.

I agree with John that there's a benefit to being one of the last speakers on. The benefits are synthesized, but there's also a down side, feeling somewhat like the guest in the Johnny Carson green room, of not losing thunder by repetition of what has gone before.

But if you will allow me, at times I will tangentially or directly say things that have been heard before. They may vary, though, because of the population that I'm experienced with and speaking about.

Cerebral palsy is a multi-handicapping neurological disorder. That is very significant, because it is not just a physical limitation or an impairment in one area of function. It always includes some physical impairment, but can also include sensory disorders, speech and language disorders, learning impairments, and possible social problems.

Cerebral palsy persists throughout the individual's lifetime, and although it presently is not curable, it is amenable to treatment.

Treatment of all multi-handicapping conditions requires multiple, interdisciplinary professional services. This is significant in the context of a discussion today, because people who work with cerebral palsy understand that if there is not an underlying network of service delivery, service to individuals is very, very limited or impaired.

If your direct service, that you know what you're doing with, requires supportive service, and then you're hooking into a new area of intervention, that requires a structure of service delivery, we will become almost multiply impaired in our delivery of service. Perhaps I could clarify that further later on.

Although the developmental problems to be solved are varied and many, one unifying goal of all treatment programs is to enable each individual to reach his or her fullest potential. One significant factor in the realization of this autonomy for multiply handicapped people is appropriate utilization of assistive devices and technology.

Now, it's been my experience that when the average person thinks of assistive devices to assist disabled people, what is usually thought of is crutches, braces and wheelchairs. That's because for decades those were the obvious kinds of support that were given for rehab services. In the past decade, the field has yielded enormous

gains in the development of sophisticated devices for people's personal development, education, and work lives.

Some of the new devices have even claimed public attention, as we saw with young Tom this morning, and the house of the police officer who was critically wounded in New York can be operated by a single switch that operates all the electrical items in the house.

It's been stated earlier that we do have plethora—maybe not a plethora, but a great deal of computerized base technology. Almost a sci-fi kind of life, this is.

But we mustn't in our interest in high tech forget the role of so-called low tech. Velcro is familiar to most of us—as a matter of fact, there's rarely any children's sports clothing that you can buy today without Velcro. There's so much Velcro in our experience now that it's put in places where we really don't need it. My own impression is that we love the sound that Velcro makes when we tear it apart.

Interestingly, in the popular science magazine, Discover, the author had listed at least 5,000 patents on Velcro. This included the possibility of using a super Velcro to hold cars and airplanes together.

The United States Government is doing research on how to make super silence Velcro, so that when officers are opening their pockets—which no longer use buttons but Velcro—there will be quiet in case the enemy can hear nearby.

The point that I'm trying to make here is that what we know as an everyday material can be generated into manifold uses when the need is expressed through creative ingenuity. It always helps if there's some potential windfall profits as well.

Velcro is also a staple product in the lives of multiply handicapped people. It holds plates on tables, secures straps and clothing, switches on mounting boards, and does literally hundreds of other product mergers in a successful way.

Velcro exemplifies that assistive devices do not have to rely on complex, computer-based technology.

No matter how simple or complex, assistive aids require creative intervention to match available resources to complex individual problems.

Assistive products range from commercial products to sophisticated, computer made technology. That is not the problem—in fact, it's the good news. The major problem that exists is the lack of appropriate delivery of these products to individuals who need them.

Assisting disabled people is not just resolved with good services. In talking about cerebral palsy populations and the developmentally disabled, the need for comprehensive service models is very, very apparent. In trying to access assistive devices, as has been said by all the speakers before, we realize that we have another source of service models that are not in place at all.

Briefly, to describe the delivery of the state of our technology, through the service models that exist, if they do at all—it's terribly fragmented and inconsistent.

The second problem that we experience, which has also been touched upon again and again in the hearing is the problem with funding. Although there are at least five funding sources, including private income, OVR, third party insurance coverage, Medicaid and

Medicare, the majority of our clients are Medicaid eligible or working poor. We have to rely on Medicaid systems which have a host of problems.

Two of the major ones—one is the inconsistency of the system and secondly the problem with its classification of medical equipment so that you could get a wheelchair through Medicaid to get a child to school but frequently you can't get them a device to help them communicate once they get there. There's certainly a problem with that.

I see that my time has run out.

We do have a listing of recommendations. If I could just summarize that—it's the Education for Handicapped Children Act. Children are going to school, and need devices to help them in getting that education through the system that already exists. This system could be improved to help get some of this assistive device funding.

Vocational Rehabilitation Act—we are still waiting for some of the regulations and amendments from the Administration which this subcommittee had recommended itself.

Finally, if I can summarize—and I do regret having to do it so early—whether the high or low tech assistive devices are chosen, the major problem that now exists is persistent and ever-growing gap between product development and product delivery.

You may recall when Alice in the earlier stages of her adventures in Wonderland came upon an extremely small entrance to a lovely garden. How she longed to get out of that dark hole and wander about among those beds of bright flowers and cool fountains, but she could not even get her head through the doorway.

What poor Alice had to do to get into that garden was truly a distracting experience of potions and cakes and telescopes and tears. All these were fine, making for a classic children's tale, but they are totally unacceptable for real-life people.

In this sense, Alice's tale does suggest a parallel to the issue of this testimony. We are discussing the dream of greater autonomy, ever visible but inaccessible except through torturous means. Hopefully, today's panels and testimonies will forge an alliance between consumers, professionals and Government to find a better way to link disabled individuals to the new assistive technologies that can better their lives.

Thank you.

[The prepared statement of Mary Ann Carrol follows:]

STATEMENT OF MARY ANN CARROL, NEW YORK CITY, NY, ON BEHALF OF UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

Good Morning! My name is Mary Ann Carrol. I am the Director of Research and Special Project for United Cerebral Palsy of New York City. I am here today to testify on behalf of United Cerebral Palsy Association, Inc. United Cerebral Palsy Association is a private, non-profit agency with 180 affiliates in 45 states concerned with meeting the needs of persons with cerebral palsy, and similar disabilities and their families. United Cerebral Palsy is very concerned with ensuring that these individuals are educated to their fullest potential, and are given the opportunity to work and live in their community. We believe that in order for this to happen these individuals must be afforded the opportunity to benefit from a wide variety of assistive technology services. Since UCP was created in the 50's, the organization has been involved in encouraging the development of assistive devices and a service system to respond to the needs of individuals with severe disabilities. Soon after the Association was formed, the Cerebral Palsy Research and Educational Foundation

was established to assist us in our goal to increase the availability of assistive technology. The Foundation has provided over $21 million dollars worth of grants to individuals, organizations and Universities for assistive technology research and development. UCP affiliates across the country assist individuals gain access to assistive technology services in early intervention, educational and adult service programs. The National Office of United Cerebral Associations is also very involved with expanding assistive technology services through the efforts of the Community Services Division. Our testimony today will outline how assistive technology can radically change the lives of persons with serve disabilities. We will also make recommendations for federal legislation that would help to eliminate many of the barriers which are currently preventing individuals with severe disabilities from meeting their full human potential. United Cerebral Palsy Inc., in New York City, is the largest voluntary service agency for persons with cerebral palsy and other developmental disabilities in the State of New York.

UCP/NYC provides comprehensive services at four Borough campuses servicing over 2000 clients and families annually throughout the New York City. These include pre-school, education, adult training, job placement, and residential services. Related health services provided include all therapies, clinic services and counseling. New programs in home barriers removal, family support services, computer training, team sports and assistive technology services are leading national models. The Agency operates $40 million budget, 90% of which is government funded. UCP/NYC runs the second largest school and program transportation system in New York.

Cerebral Palsy is a multi-handicapping neurological disorder that usually results from an injury to the brain of a developing fetus, newborn, or during the early developmental years. This injury, or lesion, results in a wide spectrum of physical impairments which may also be accompanied by sensory deficits, speech and language, learning and social problems. Cerebral Palsy persists throughout the individuals's lifetime and, although it is not presently curable, it is amenable to treatment.

Treatment of a multi-handicapping condition requires multiple and inter-disciplinary professional services, including physicians, therapists, special educators, vocational counselors and social workers. Under the best conditions, these varied professional work in team setting to solve the multiple problems that any one individual may have over the course of different stages of development from infancy through childhood and into adulthood.

Although the developmental problems to be solved are varied and many, the one unifying goal of all treatment programs is to enable each individaul to reach his or her fullest physical, educational and social potential. One significant factor in the realization of this autonomy for a multiply handicapped person is the appropriate utilization of assistive devices and technology.

When the average person thinks of devices to assist the disabled person, what usually comes to mind are crutches, braces and wheelchairs. For decades, with some minor variations, these were the staple items of rehabilitation services. In the past decade, however, the medical, therapeutic and rehabilitation fields have yielded enormous gains in the development of more sophisticated devices to assist disabled individuals in their personal, educational and work lives.

Some of these newer assistive devices have even captured the public's imagination because of their technological wizardry. Imagine being able to control every electric item in your household including windows and doors with a simple switch from a centralized control box. This is sci-fi come alive, and is currently possible, and for some individuals makes the difference between living independently at home or dependently in an institution. Other examples of astounding assitive technology include computer base communication devices that speak in male or female versions of a child's or adult's voice, and robotic aids.

The application of this so-called high technology to rehabilitation and education is a very important and significant development because it can make a dramatic difference in a disabled person's life and because it stretches the imagination toward further possibilities. In our excitement and support of high tech, we must not lose sight of the broader-bases so-called low technologies that also exist and that can be successfully applied toward the goal of increased functioning and autonomy for many multiply handicapped individuals.

We have all experienced the product called velcro. This handy product comes in two parts with one soft fluffy side and the other side rough-align them together and an immediate compact seal is made. Virtually every item of sports and children's apparel has at least one strip of velcro on its pocket of cuffs. As a matter of fact, velcro has probably been put in places where there is no need for it at all. Its purpose in these super-duper velcro versions, I suspect, has more to do with the intrigu-

ing sound it makes when its peeled apart—an ever-ready sound of action and alertness, than for any utility it serves. In a recent article in the popular magazine, Discover, Judith Stone refers to velcro as the "final-frontier". The article was very revealing, even to an alert velcro watcher, such as myself. It reported that there are at least 5,000 patent of this might product, including ones that hold cars and planes together as well as a super-silenced version for governmental issued armed forces uniforms.

The point I am trying to make is that even what we come to know as everyday materials can be generated into manifold uses when the need is expressed through creative ingenuity and potential windfall profits. Velcro is also a staple product in the lives of the multiply handicapped individuals. It holds plates on tables, secures straps and clothing, switches on mounting boards and does literally hundred of other product mergers in a quick successful way. Velcro exemplifies that assistive devices do not have to rely on complex computer based technology and that, no matter how simple or complex, assistive aids require creative intervention to match available resources to complex individual problems.

A host of assistive device products ranging from readily available commercial materials to sophisticated custom-made computer technology already exists. That is not the problem, in fact, it's the good news. The major problem that does exist, however, is the lack of appropriate delivery of these products to individuals who need them. Assisting disabled people is not just solved with goods it also requires services.

Basic to any professional support services is the capacity to provide meaningful evaluation, informed product selection, education and training, follow-up and, of course, the means to purchasing for appropriate candidates. Logically, consumers therapists, physicians, and educators need to access assistive devices in order to yield their immediate benefits. It also follows that consistent access leads to an increased experiential base which can then inform future technological developments. At best, comprehensive services models for the delivery of state of the art technology and assistive devices to multiply-handicapped people is fragmented and inconsistent. The result if this condition is diminished potential for multiply-handicapped people, for professional knowledge, and for society.

Another, and perhaps more obvious problem, is the issue of funding, particularly as it applies to higher cost technology such as communication devices and environmental controls. There are four primary sources of funding: (1) personal resources; (2) third-party insurance coverage; (3) Medicaid; and to a lesser extent (4) Medicare. Since the majority of our agency clients are working poor or medicaid eligible the more potent fiscal resource of personal funds and insurance coverage is not available to them. This leaves Medicaid as the primary financial resource, and the problems with Medicaid are legion. One, of the primary problems experienced by our agency and clients is that Medicaid, as a funding source does not include newer rehabilitation devices medical equipment which it does not define precisely. Under the system of Medicaid, wheelchairs that enable you to get to school are acceptable but devices that allow you to communicate once you get there sometimes are not. The presently approved Medicaid list should be re-examined to make it more responsive to real needs of real people even in this current century.

The Medicaid system does allow for a system of "fair-hearings". United Cerebral Palsy of New York City, Inc. has called for many a "fair-hearings" and has never been denied a case after its argument was heard. Such "fair-hearings", however, require the resources of an experienced social agency not available to most individuals on their own. Furthermore, the expenditure of time and energy by private individuals, private agencies and municipalities is considered to be a waste of time and energy better spent on the development of programs that will expedite services rather than deter them.

As important to improving the payment system for assistive devices is the need to strengthen the States ability to provide assistive devices through the Education of all Handicapped Childrens Act and Vocational Rehabilitation Act of 1986. Until, these and other State agencies in cooperation with community based agencies are able to respond to need of children and adults whose lives depend on technology to receive an appropriate public education, and work and live in the community we have not taken full advantage of the power of technology.

UCPA would like to commend the Chairman and the members of this subcommittee for their interests in expanding federal policy in the area of assistive technology services. United Cerebral Palsy believes well thought out legislation in this area will allow many individuals with severe disabilities to be educated with their non-disabled peers, work in diverse business settings and live independently in the community.

THE EDUCATION FOR ALL HANDICAPPED CHILDRENS ACT P.L. 94-142

Many children with severe disabilities need assistive technology services in the classroom and at home to benefit from education and related services, but many states deny children these services. States are also unable to evaluate and train students for assist technology because of lack of personnel. United Cerebral Palsy receives thousands of calls a year from distressed parents asking for help in accessing assistive technology and learning how to use it. We also receive calls from parents who are upset because their children are not allowed to bring their assistive technology devices home with them from school. This is a very disturbing situation for a parent of a child who is dependent on augmentative communication. These parents have no tool to communicate with their child at home. These parents are also very concerned that their children will suffer further communication difficulties because of limited access to their technology. We, therefore, look to this Committee to clarify that a free and appropriate education under EHA includes assistive technology services for children who need it as part of their individualized education plan.

We are very encouraged by the leadership Representative Major Owens has shown this year by introducing The Technology to Educate Handicapped Children Act H.R. 1658. We believe this legislation would begin to elevate many of the concerns UCPA has about technology coverage in the Education of the Handicapped Act, because it will assist States in developing a statewide delivery system which would allow severely disabled children to receive the assistive technology they need.

THE VOCATIONAL REHABILITATION ACT OF 1986 P.L. 99-506

This Select Committee was instrumental in ensuring that the rehabilitation engineering services amendments were added to the Vocational Rehabilitation Act of 1986. This Committee responded to testimony that demonstrated the important impact rehabilitation technology services have in assisting severely disabled adults to become employed. Yet a year and a half after this important legislation was passed the Rehabilitation Services Administration has not issued regulations on these amendments or given states any guidance on how to carry out these amendments. We therefore encourage this committee to pass legislation that assist States to build their capacity to provide rehabilitation technology services and implement the 1986 Amendments.

Since World War II this nation has put a great deal of money into researching and developing assistive technology devices. This year alone NIDRR will spend 16 million dollars on rehabilitation engineering research. We must now create a Federal sysem for ensuring that severely disabled individuals have access to these assistive technology devices and services, while building the capacity of states to provide assistive technology under The Education for all Handicapped Children's Act and the Vocational Rehabilitation Act. United Cerebral Palsy Association believe Congress could do this by creating an incentive grant program to assist states in building their capacity to delivery assistive technology services in the home, the classroom, and the workplace.

COMPETITIVE INCENTIVE STATE GRANT PROGRAM

Five year grants would be awarded on a competitive basis to states for planning and development of a comprehensive statewide system of assistive technology servvices.

A State's application must include at a minimum:

(1) Documented support of the application from the State Education agency, Department of Vocational Rehabilitation, Part H Lead agency, Office of Maternal and Child Health, the Department of Mental Retardation/Developmental Disabilities, State Medicaid agency and the Office of the Governor for interagency planning and cooperation in the delivery of assistive technology services.

(2) The establishment of a State Advisory Council on Assistive Technology services. This Council shall be composed of representatives from State agencies which will be part of the interagency planning, organizations which are active in advocating or providing assitive technology services, persons eligible under this Act for services, businesses with an interest in researching, developing and providing assistive technology, and other individuals with an appropriate interest as chosen by the Governor.

(3) A description of past and current state efforts to plan and develop a statewide system to deliver assistive technology services.

(4) An explanation of such a system will seek solutions to the problems of accessing assistive technology during transition from early intervention to public educa-

tion and from secondary education to post-secondary education and adult service systems.

(5) A description of a comprehensive training program for parents, professionals across multiple disciplines, and individuals with disabilities to increase their understanding and involvement with assistive technology. Such a training program should include both inservice and preservice components.

(6) Describes the priorities and a five year timeline for development of a statewide system which by year

(a) estimates the number of individuals to benefit from assistive technology increases each year.

(b) with projected plans of operation, including development of described services delivery system and increasing interagency coordination.

(c) describe methods for increasing private sector, not for profit and not profit corporations participation in the delivery of assistive technology.

(d) describes the methods for financing and funding assistive technology to increase access for users;

(e) and explains system of quality assurance.

UCPA recommends an authorization level of ten million dollars to begin to involve states in this competition to achieve permanent system change.

In addition, to the capacity building grant program, UCPA makes the following four additional legislative recommendations.

FEDERAL LEADERSHIP

National Assistive Technology Advisory Council

We urge Congress to establish a National Assistive Technology Advisory Council with representatives from the public and private sector. The purpose of this Council would be to review Federal funding policies that are currently impeding the delivery of assistive technology services. The Council would report their findings and recommendations to Congress one year after it is established. As you have heard here today we have many different types of assistive technology commercially available for disabled individuals. But even when disabled consumers know about these devices they are unable to benefit from them because of current federal funding practices. We believe the formation of a National Assistive Technology Council would assist Congress in creating federal policy that would economically allow many more severely handicapped individuals to benefit from what is already available.

Department of Education

We believe in order for a Federal initiative in Assistive Technology services to become a reality the Department of Education needs Staff in each Division of the Office of Special Education and Rehabilitation Services (OSERS) and the National Institute of Disability and Rehabilitation Research (NIDRR). We also believe it would be most beneficial to establish a new Deputy Assistant Secretary Position in OSERS to coordinate the Departments assistive technology initiative efforts.

Federal Loan Fund for Assistive Technology Services

United Cerebral Palsy encourages Congress to enact legislation which would create a new Federal Program to assist disabled individuals finance their devices. By creating such a fund Congress would be solving some of the difficulties individuals face in purchasing assistive technology. Such a program could help encourage more states to replicate successful loan programs, as have been established in New York, California, and Vermont.

Public-Private Partnerships in Assistive Technology

UCPA recommends the establishment of a new demonstration program within the National Institute on Disability and Rehabilitation Research (NIDRR) to encourage public private partnerships in assistive technology services. The Director of NIDRR would be able to make grants to and contracts with States and public and private agencies in cooperation with business and industry to

(1) establish or develop new approaches to financing and funding assistive technology; or

(2) expanding the delivery of assistive technology services that enable infants, children, and/or adults with disabilities to become more independent and increase their interacting with their family and non-handicapped peers. UCPA recommends on authorization level of ten million dollars to attract private section interest in this important program. Credits for Business which purchase assistive technology devices for individuals with disabilities.

TAX CREDITS FOR BUSINESS WHICH PURCHASE ASSISTIVE TECHNOLOGY DEVICES FOR INDIVIDUALS WITH DISABILITIES

United Cerebral Palsy Association encourages Congress to pass legislation introduced by Senators Tom Harkin and Lowell Weicker, Jr. which amends the Internal Revenue Code of 1986 to allow business to deduct the cost of acquiring or modifying any property which is specifically designed to enhance the employability and productivity of a disabled worker.

Currently, section 190 of the Internal Revenue Code allows businesses to deduct the expenses they incur for removing architectural and transportation barriers facing disabled employees. Thus, the underlying concept of this bill is complimentary to current law.

In summary, whether it be high or low-tech based assistive devices, the major problem that now exists is a persistent and ever-growing gap between product development and product delivery. The weakest link being the absence of an integrated system of efficient service delivery that joins consumers and professionals to available and developing assistive device technologies.

You may recall that Alice, in the very earliest stages of her adventures in Wonderland, came upon an extremely small entrance to a very lovely garden. "How she longed to get out of that dark hall and wander about, among those beds of bright flowers and cool fountains, but she could not even get her head through the doorway;". What poor Alice had to do to enter that garden was truly a distracting experience of potions and cakes and telescopes and tears. All these were fine making for a classic children's tale but they are totally unacceptable to real-live people. And, in a sense Alice's tale does suggest a parallel to the issue of this testimony for we are discussing the dream for greater autonomy ever visible but inaccessible except through tortuous means. Hopefully, today's panels and testimonies will forge an alliance between consumers, professionals and government to find a better way to link disabled individuals to the new assistive technologies that can better their lives.

Mr. OWENS. Thank you.

Mr. Hahn?

STATEMENT OF MR. ROLAND HAHN, DIRECTOR, CENTRAL PENNSYLVANIA SPECIAL EDUCATION RESOURCE CENTER

Mr. HAHN. Mr. Chairman, I'd like to give you an overview of how the Pennsylvania Department of Education has begun to address some of these assistive devices issues and service delivery needs.

I'm director of the Central Pennsylvania Special Education Regional Resource Center. Public Law 94-142 Discretionary Funds, enable our resource center to provide technical assistance and staff development services for local educational agencies who work with students with disabilities.

While educators are generally somewhat more aware of the role that microcomputers can play in standard practice, they are often unaware of the more sophisticated technology and its application in Special Education. As reliable assistive devices became available, it became apparent that educators would need help in becoming aware of these devices and their application in education.

In 1984, the Pennsylvania Department of Education, Bureau of Special Education formed a state-wide assistive device center, or ADC, as it's referred to. This Center was felt to be necessary since individual educators were unable to keep abreast of technological developments in the assistive devices field.

The Pennsylvania Assistive Devices Center was therefore developed to provide consultation, training, and resources regarding use of state-of-the-art, high-technology assistive devices by students with disabilities.

The staff of the ADC consists of two secretaries and five professional staff. I intentionally kept this staff small to enable them to keep direct, personal contact with major device manufacturers and resource center directors and research center directors throughout the country, and to enable them to provide feedback to each other as they go about their business.

The major goals of the ADC are collection and dissemination of assistive device information, training of LEA staff in assessment and use of assistive devices, and providing assistive device systems for students with disabilities.

We disseminate information in a quarterly newsletter distributed to thousands of educators. Fact sheets are summarized, including a wide variety of assistive device topics that have also been developed.

We have developed training videotapes on assistive device use and have developed and maintained a library, including thousands of reference books, journals and software. All these items may be borrowed free of charge by Pennsylvania educators and others working with students with disabilities.

Consultation services are also available. Our staff can be contacted through a toll-free hotline number to discuss any questions that parents or educators may have regarding assistive device use.

Center staff frequently conduct in-service training programs, and are also available to meet with educators at their school to discuss students and their assistive device needs.

Planning an effective assistive device delivery system involves overcoming many challenges. Students who truly need assistive device technology are low incidence in a population of severely handicapped students. Teachers of these low incidence students are frequently far distanced from colleagues and have few opportunities for professional interactions around assistive device technology.

Other professionals, like speech therapists and occupational therapists, frequently have changing caseloads and experience relatively high professional turnover. These can cause difficulty in building assistive device technology skills among classroom teachers and related services staff.

Some Statewide programs have attempted to evaluate students' assistive device needs through the use of clinics. This medical model involves students and families travelling sometimes very great distances to perform unfamiliar tasks in very unfamiliar environments. This form of one-shot evaluation is very inadequate, I feel.

No matter how good the evaluation indeed is, of greatest importance is whether or not the assistive device system actually ends up helping the student and the family. Unfortunately, parents and students frequently become excited about the possibilities of assistive device use only to find out that funding is unavailable for the purchase of the device.

Parents, students, and local educators can also be frustrated by a lack of follow-along services regarding initial configuration of the system, needed modifications, and ongoing use of these assistive devices.

In Pennsylvania, we therefore developed a local augmentative specialist system, whereby approximately 100 LEA staff have been

selected to receive extensive training by our assistive device center staff. This gives local educators a sense of pride in their advanced training and an ability to professionally support one another in their local area.

These local augmentatives specialists are targeted for advanced training each year by our center and have been provided with starter set-up materials to use in assessing students' appropriateness for assistive device use.

After assessment, the desired assistive device system can then be borrowed from our assistive device center for a three-week trial period. Since some of these systems can cost in excess of $5,000, this ability to borrow the devices on the short term through the assistive device program provides a great deal of relief from pressure that local educators are often faced with in terms of having to make the perfect choice of device the first time.

Without this type of program, many assistive devices end up on closet shelves, since educators are at times afraid to admit that they've made a less than perfect device choice.

Once the device has been shown to be appropriate, educators may apply for a long-term loan for an assistive device system. This long term loan program is truly the key to our assistive device center's success.

For each of the past three years, we've managed a program whereby educators wrote competitive grants for assistive device systems—total systems—for their students. Educators knew that the competition was keen for these grants, and they therefore needed to become more knowledgeable about assistive devices, and more importantly, needed to have very carefully analyzed their students' skills and determined needs for the devices.

It is important to note, however, that these devices are placed on long-term loan to individual students, for use as long as the students require these devices, throughout their entire school careers. Local education agencies must agree that the devices be made available to the students 24 hours a day, 365 days per year. This procedure involves parents being able to utilize the devices with the students at home, increasing the benefit of the devices.

During the past three years, 416 device systems have been distributed to students throughout the Commonwealth. The total amount of funds dedicated to this long-term loan program per year in these three years has been $500,000 per year.

Another important factor in this program is that the assistive device center guarantees that the devices can be exchanged should they be outgrown by a change in the student's physical or educational development throughout that child's school experience.

Basing this long term loan program through a Statewide center allows this hardware exchange program to be able to operate. Individual schools purchasing small numbers of devices for small numbers—relatively speaking—of students would be unable to operate this essential type of exchange and upgrade program.

Utilizing local augmentative specialists' model enables more students to be able to be evaluated and served than any single team of experts could manage. It empowers LEA staff to be part of the decision-making process regarding assistive devices and use of technology.

For the model established in Pennsylvania to work, however, the long-term loan program is essential. Federal funds are needed to ensure that these needed assistive devices are available for use by students with disabilities.

It's only through the use of these assistive devices that many of these students with disabilities are able to effectively communicate either orally or in writing. These communication skills are essential if these students are to be given an opportunity to maximally benefit from education programs and to participate more fully in society.

It's appropriate that the technology assistance bill has identified States at the level at which services can be developed and expanded. One other consideration might be the use of national or regional resource centers to form regional consortia for provision of assistive device services.

For example, Pennsylvania provided with funds could assist other States in the Great Lakes Area Regional Resource Center and our National Center regional area to develop assistive device services.

Many States have asked us for this type of consultative assistance in the past, and our ability to provide this on-site training has been limited because of lack of funds.

Again, stressing as others have the need for more definitive interagency planning and cooperation within the States is absolutely essential. It's particularly essential as students are transitioned from the umbrella of 94-142 types of special education services and related services into the world of work or into supported employment or community living experiences, whichever it happens to be.

I commend your efforts for developing this legislation, addressing these crucial needs for assistive devices, and the policies outlined in the Federal State Assistive Technology bill.

Thank you for this opportunity to share information with you.

[The prepared statement of Roland T. Hahn II, follows:]

TESTIMONY OF ROLAND T. HAHN II, DIRECTOR, PENNSYLVANIA SPECIAL EDUCATION REGIONAL RESOURCE CENTER

This document includes information written and presented by Roland T. Hahn II, Director of the Pennsylvania Special Education Regional Resource Center, and members of the Pennsylvania Assistive Device Center staff (Mary Brady, Coordinator, Colleen Haney, Augmentative Communications Specialist, and Karen Kangas, Seating and Positioning Specialist) at the National Planners Conference on Assistive Device Service Delivery. This conference was sponsored by the Great Lakes Area Regional Resource Center, Columbus, Ohio, in April 1987.

PLANNING SERVICE DELIVERY SYSTEMS

Ten years ago LaRocca and Turem (1978), writing for the Urban Institute, characterized the state of rehabilitation technologies in the U.S.: "Currently, only a fraction of disabled Americans are able to benefit from existing technologies that would improve the quality of their lives. A national commitment is needed to assure that all disabled Americans regardless of the nature of their disabilities or their financial status can secure and utilize any proven technologies that will enable them to lead more productive, functional, and statisfying lives." Only a few years ago, Blaschke noted the following situation: "For a society so adept in developing technology, we have been inept and indeed negligent in developing the political, social, human and organizational innovations to apply that technology in such a way that its benefits can be realized." (Blaschke, 1986)

These statements might be interpreted to mean that during the past ten years no progress has been achieved in providing individuals with handicaps access to high

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technology systems. Although we often become impatient with a seeming lack of progress, perspective must be maintained regarding the contemporary nature of assistive device technology. Fifteen years ago the special education needs of students with handicaps were, by today's standards, underserved and were frequently unserved. Approximately ten years ago the enactment of P.L. 94-142 provided impetus to enhance special education services. Only during the past five years have microcomputers and small-sized portable assistive devices been generally available to help meet the needs of individuals with severe disabilities.

Additionally, as a low incidence population, persons with severe handicaps represented a relatively small voice of consumers. Their needs were often overshadowed by the typically less complex needs of higher incidence populations. Although action committees, lobbies, etc. quickly formed to voice and advocate for the needs of individuals with mental retardation, learning disabilities, etc., individuals with severe and multiple handicaps, for whom sophisticated technology, systems held extraordinary promise, often sought solutions and services individually or in very small, relatively unorganized groups.

Following enactment of P.L. 94-142, local education agencies (LEA) were responsible for providing services to students with handicaps. The prevailing model for delivering services to children with handicaps evolved in large urban areas and typically involved employing highly trained professionals. This model was found to be inappropriate for many areas of the country where populations are not large enough to ensure cost effectiveness in this type of delivery system. "Alternatives to this model have been to place children far from home in residential facilities, to require extended travel to obtain services, or to provide no services at all. These options are unsatisfactory in the light of both federal mandates and the growing evidence that there is educational value in leaving children in their home environment and in integrating as much as possible handicapped children with nonhandicapped children" (Werdin, 1984). Least restrictive environment concerns, very recent successful application of emerging high technology to meet students with handicaps needs, and a public readiness to support assistance efforts have very recently combined to encourage a renewed look at service delivery models. Unfortunately there has been precious little research information upon which to base decision making.

Planning is a necessary starting point to develop service delivery methods to meet the assistive device needs of individuals with handicaps. The type and amount of planning initially needed and the amount of energy needed to be expended on this effort will vary greatly in different areas depending upon the state-of-the-state, priorities that exist in regional service areas, and the perceived need for efforts and funds to be directed to assistive device services by everyone in the area from LEA practitioners to state education agency (SEA) administrators. Someone must, however, initiate action by identifying a needs and devising a draft method to meet the need and solve problems.

Planning Issues

The level at which the problems and needs are identified and the fiscal commitments that can rapidly be brought to bear will significantly determine the direction and level of initial planning needed. If a lead agency (e.g. a SEA), has determined that the problem is a high priority and allocates funds to meet needs at the state level, services delivery can be initiated quickly, pilot programs can be activated, and program planning can indeed be concurrent with the initial direct services efforts. If, however, start-up funds are unsecured, services needs are not clearly defined, and no lead agency has emerged, more deliberate preservice planning is needed.

Regardless of the level at which planning and service ideas are initiated (local, regional, state) numerous issues related to planning must at some point be discussed and resolved for an organized, effective service delivery system to meet changing needs and to maintain needed services over time. An analysis of the philosophy of the effort should be one of the first issues addressed. A determination should be made that there is truly a need for action and that the proposed efforts are a high priority for services consideration. A determination should be made that other groups share the feeling that proposed services are needed.

If a lead agency has not emerged, or the agency from which the original ideas for services needs is not in position to provide leadership to facilitate planning, an individual or agency must be encouraged to accept this role. An individual must accept responsibility for developing an initial outline as a starting point for discussion. From this outline can emerge draft (idea stage) short and long range goals. The draft should identify initial target populations to be served dependent upon: projected funding levels; non-duplication of existing services; and ability to provide services to meet short range goals.

Support and commitment for the planning effort should be gained at the earliest possible time. Communications must be established with state, regional, or local level administration depending on the level of initial services focus. Advantages of the project should be discussed. Emphasize that the planned services are part of their mission. Cost saving data should be presented.

After general support is gained from key leaders at different service delivery levels, individuals and agencies to be involved in the planning group should be identified. Depending on the level of planning to be pursued, either state level heads of agencies could be brought together for discussions, or individuals could be designated by state agency directors to participate in the planning process.

To reduce ambiguity and provide a common base for discussion, awareness level training should be provided to all planners. This effort could include showcasing state-of-the-art assistive device technology to stimulate additional ideas regarding services goals to be pursued. Following the awareness activity, initial planning sessions should be held as input meetings to review, revise, expand or reduce the draft services document. The planning group should develop subcommittees as needed and set timelines to finalize all details needed to initiate services. The planning group needs to also consider the needs for monitoring services delivery progress. Data should be collected regarding the programs that are initiated to determine benefits provided to consumers of the services and to monitor the need for any future changes in services. The planning group will also need to be concerned with efforts to stabilize funding sources for development and continuation of long-term service delivery systems.

In 1982, the Office of Technology Assessment (OTA) concluded in a report "Technology and Handicapped People", that "despite the existence of numerous, important problems relating to developing technologies, the more serious questions are social ones—of financing, of conflicting and ill-defined goals, of hesitancy over the demands of distributive justice, and of isolated and uncoordinated programs" (OTA 1982). The Pennsylvania Department of Education recognized the need for planning and program development that could lead to delivery of tangible programs and services to directly benefit students with handicaps. In 1984, Gary Makuch, Director of the Bureau of Special Education (BSE) for the Pennsylvania Department of Education (PDE), indicated that some P.L. 94-142 discretionary funds would be directed toward meeting assistive device services needs and suggested that an action plan be drafted to meet these service needs of Pennsylvania LEAs and students with handicaps. Pennsylvania had an established Special Education Resource System of projects designed to develop programs and provide technical assistance to LEAs regarding the needs of students with handicaps. As director of the Central Pennsylvania Special Education Regional Resource Center (SERRC), I developed a draft of goals and objectives and objectives to be accomplished by an Assistive Device Center (ADC) to be managed by the SERRC. The draft was reviewed and input was provided by BSE staff.

Planning Steps

Planning to develop the Pennsylvania service delivery system initially involved a variety of information gathering efforts. In 1980 the National Association of State Directors of Special Education (NASDSE) conducted a study of existing assistive device service delivery systems and found that "while some centers for assistive devices do exist, none provide comprehensive services." The NASDSE document "Assistive Devices for Handicapped Students: A Model and Guide for a Statewide Delivery System" was used to help prioritize initial program objectives. Input regarding the assistive device services model was sought from numerous nationally recognized assistive device service providers including the Trace Research and Development Center, the Children's Hospital at Stanford, the Maryland Rehabilitation Center, the Tennessee Rehabilitation Engineering Center, etc.

An initial plan for delivery of assistive device services through the ADC was developed and included the following major components:

Staffing: hire program coordinator and recruit/hire an augmentative communications specialist and a rehabilitation engineer.

Awareness: conduct a state-wide awareness conference to provide LEA and regional staff with information on state-of-the-art assistive devices and information on how these systems can specifically enable students with handicaps to best benefit from their educational program.

Information Dissemination: gather and disseminate assistive device information statewide via newsletter, electronic bulletin boards, and direct communication with practitioners via a toll-free hotline.

Training: develop training materials and conduct workshops at LEAs and on a regional basis throughout Pennsylvania. Work toward developing a network of local experts and provide intensive training for this group.

Provide Assistive Device Systems for Student/LEA Use: develop a short-term loan program to provide systems to LEAs for evaluation of students' assistive device needs. Provide assistive device systems for individual student use (available twenty-four hours per day, twelve months per year, at home and at school) by establishing an assistive device long-term loan program.

Conduct Long-Range Plans for Assistive Device Services: continue to analyze needs assessment data and coordinate efforts to produce a memo of understanding among service delivery providers state-wide.

Additional planning activities conducted by the Pennsylvania ADC, following establishment of the program, included development of an advisory committee comprised of special education administrators, supervisors, higher education faculty, speech therapists, and classroom teachers. This committee meets at least annually to provide input regarding services needs in the state and to provide reaction to proposed ADC services. Informal meetings and discussions are also held with a wide variety of program administrators and service providers representing assistive device programs throughout the United States. These nationally recognized experts provide excellent feedback regarding the new services ideas proposed by the ADC. The ADC also sponsors symposia to have national assistive device leaders meet to discuss services needs that can be addressed by the ADC.

Program Strengths and Weaknesses

The Pennsylvania model for service delivery via the ADC was able to address many of the planning issues originally detailed since a start-up funding source was available at the onset of planning and a Resource Center, familiar with program development, acted as the lead agency to coordinate planning and initiate services. The original draft of goals and objectives was easily completed since the primary author had experience in program development for populations that can benefit from assistive devices. The SERRC, the managing project of the ADC, had access to input from LEAs and regional service providers to initiate a network of communication regarding services needs. The SERRC's past history in providing quality training programs gave credibility to awareness activities and initial training programs. ADC staff members' frequent interchange of ideas with nationally recognized experts in the assistive device field enabled the ADC to get rapid and candid feedback on proposed or previously initiated services and procedures.

An incomplete aspect of the ADC program to date is that the goals regarding interagency planning, hopefully leading to a letter of understanding among service delivery providers in the state, has not yet been fully accomplished. At the present time, interagency planning efforts consist of the participation of the ADC Coordinator as an active member of the Office of Vocational Rehabilitation Engineering Advisory Committee. Committee members represent many state/private agencies which would be involved with assistive technology services for all Pennsylvania citizens who require assistive devices. Its mission is to assist in planning coordinated technology services for vocational rehabilitation students under the requirements of the 1986 amendments to the Rehabilitation Act. The ADC has been specifically called upon to share aspects of its currently operating service delivery program which might be successfully applied to a broader range of services for a wider population in the state.

In March of this year, the ADC responded to a Request for Proposals from the U.S. Department of Education, Office of Special Education and Rehabilitative Services (CFDA Number 84.180A), "Innovative Cooperative Models to Expand Technology Benefits." This proposal, if accepted, would provide transitional technology services for graduating high school seniors who have been served by the ADC during their public school involvement, and now require continuation of equipment, ongoing assessment and implementation help to successfully attend a college, complete vocational training, or to obtain a job and increase independence. Our goal in serving graduating students during this crucial transition period is to create and demonstrate a working mechanism whereby such services can be eventually coordinated between the state Bureaus of Special Education and Vocational Rehabilitation.

In the first three years of the Assistive Device Center's existence, resources were directed toward information dissemination, training LEA staff in assessment and use of assistive devices, and toward providing assistive device systems for students with handicaps. Having other state agencies and regional service providers united toward the goal of providing persons with handicaps lifetime access to assistive devices would enable this goal to be realized. No one agency can provide all the

needed services to all populations at all age levels. While the ADC has been attempting to help meet the assistive device needs of special education students age three to twenty-one, the present need is to complete planning efforts linking all agencies into a comprehensive statewide services delivery program.

Consideration should also be given to providing federal funding to enable existing Assistive Device Centers in the United States to help other states to establish, enhance, and maintain quality, a state-of-the-art assistive device centers in each state. By providing additional funds to the National Regional Resource Centers (RRC), the Pennsylvania Assistive Device Center could act as the program in our seven-state Great Lakes Regional Resource Center (GLARRC) area to share information, provide technical assistance, etc. to the other states in the GLARRC area. This method could help insure that all states were keeping abreast of technology applications in education, and could provide a mechanism to cost effectively share existing expertise throughout the United States.

IMPLEMENTATION—SERVICE DELIVERY: EXPERIENCES IN PENNSYLVANIA

Since the Assistive Device Center in Pennsylvania is funded by the Pennsylvania Department of Education, we direct our services primarily to meet the needs of students and educators. Consequently, we use a purposely narrow definition of the term "assistive device." The needs of multiple-handicapped students are complex, vast and many are still unmet. The Pennsylvania Assistive Device Center is attempting to satisfy the needs of physically and/or mentally multiple-handicapped students in our state for writing, oral communication and some degree of environmental control. We do not directly address mobility, transportation, recreational or independent living technologies. To a lesser degree, we have provided some sensory aids, for students with vision or hearing handicaps.

Whether you call this area of concentration "assistive devices," "rehabilitation technology", "adaptive devices", "electronic aids" or "high-technology systems", confusion about what, specifically, we are talking about is rampant. Consumers, professionals and the lay public alike experience varying degrees of misinformation, unrealistic expectations, or simply lack of adequate information about what exists in terms of technological aids, and how such information can be applied. A number of months ago I was asked to provide a definition of the term "assistive devices" by the editors of the Encyclopedia of Special Education. A portion of that definition follows:

Definition of Terms

The term assistive device has been applied to a wide range of highly specialized mechanical, electronic, and computer-based tools which are now commonly used in rehabilitation and special education settings. The assistive device is typically designed to perform a particular prosthetic or orthotic function, but it is not a prosthesis nor an orthosis in the traditional medical sense. (Reynolds & Mann, 1987)

This functional definition goes on to include sensory aids, communication aids, computer access devices, and aids to daily living. Writing aids and special-function or adapted learning tools such as a specially-mounted commercial device, for example, a calculator or cassette tape recorder with sliding control to ease operation are also considered assistive or adaptive devices. The term "assistive device" is preferable, because it relates to the function of the article, rather than to its derivation. Such devices may, in fact, be commercially available as special function items, adapted from mass market items, or a combination of both. Most assistive device systems contain components of each, such as the typical Apple computer configured with an adapted keyboard and a customized switch or headpointer.

Educators are not the only professionals currently struggling to define this realm. The Institute on Rehabilitation Issues, a consortium of vocational rehabilitation experts, provides this guidance:

"Rehabiliation technology includes compensatory strategies and adaptive equipment to increase or improve the functional capabilities of persons with disabilities. It is used to enhance the vocational, educational, and/or independent living opportunities for persons with disabilities. It may be further defined as technological methods of achieving practical purposes in the rehabilitation process. Devices, equipment, and strategies used in this process may be individually created or may be adapted from available equipment or strategies." (Thirteenth Institute on Rehabilitation Issues, 1986).

Note that the IRI definition of "rehabilitation technology" is slightly broader than the Encyclopedia of Special Education's definition of "assistive devices". This reflects the appropriate life-spectrum concerns of the two areas: learning tools for students and vocational/independent living devices for vocational rehabiliation stu-

dents. Included in the IRI definition are biomedical technologies, wheelchairs, adapted vehicles and architectural modifications, as well as non hardware-intensive strategies, such as job sharing.

Apart from vocational rehabilitation, service delivery in the area of assistive technology has also been provided by speech and language clinics, medical facilities, in research and development settings, by volunteer organizations such as the Telephone Pioneers of America and by durable medical equipment (DME) dealers. Although this is a new area to special education, these other types of service providers have been involved in the areas for many years, albeit without a coordinated or comprehensive approach, and with spotty results. (Office of Technology Assessment, 1982.)

The various components of service delivery include clinical, training and equipment provision aspects. Clinical services include assessment and evaluation (what available materials are there in terms of student needs, capabilities and the technology and how well is it all working together?) and therapy (formal, goal-oriented practice with the device). The training areas are: training the end-user (student), training caregivers (teachers and therapists), and training parents and significant others (aides, attendants, siblings). The major concerns with regard to equipment are the (1) allocation of resources and, (2) the logistics of distribution.

Overview of Service Delivery Issues

With regard to providing communication aids, environmental controls and computer access systems to end consumers there have been two seemingly insurmountable problems: funding high cost device systems and provision and ongoing student evaluation, training and follow-up therapies. In the past, locating a device which could provide the needed functions was also somewhat challenging. That, at least, has changed considerably with the current flock of multi-functional devices which can be accessed using a number of input techniques, and which in turn provide a wide number of output options.

The reasons given for the funding problem range from the relatively high cost of systems ($2,000–$12,000) to the inadequately documented efficacy of these tools as vocationally or educationally sound and necessary expenditures. Lack of professional expertise and available services for describing, then locating or designating the devices, obtaining training for their use and providing accompanying therapies (occupational, physical and speech/language) is well known. The widespread availability of this technology is so recent that colleges are only beginning to offer comprehensive professional or pre-professional training programs for these disciplines using state-of-the-art technologies. Speech therapy and special education training at the graduate and undergraduate levels have not generally kept pace with current technology practices. At present, only a handful of college programs training speech therapists offer even one course in augmentative communication. Instead, such efforts have evolved outside the traditional training grounds, through inservices, manufacturers' workshops, conferences and continuing education offerings. Consequently, expertise is still diffuse, and its development is not yet well-supported.

The approach taken by the Pennsylvania Assistive Device Center addresses these problems in a new way by achieving a critical mass of technology availability and awareness in a segment of the target consumer population. With adequate equipment, technical support and opportunities to participate in training activities, a strong local network of expertise naturally forms. Using this approach, economies of scale and a cost-effective, ongoing service delivery system are being built for the school-aged and preschool aged subset of the total student population which could benefit from the judicious application of these technologies. Our program is in its fourth year of operation. Feedback from the service consumers (teachers, therapists, students) and from professional colleagues has been strongly supportive of the approach. Results are being continuously monitored through daily contact with local specialists and administrators, as well as more formal advisory processes and user surveys.

A Description of the Pennsylvania Service Delivery System

The Pennsylvania Assistive Device Center provides appropriate and necessary technology to preschool and school-aged handicapped children in the state of Pennsylvania. Inservice training for educators, ongoing technical assistance, technical hot-line service, print resources, etc. are also provided by the Assistive Device Center. The project has focussed more heavily on communication, writing and computer access aids than on sensory, environmental control, mobility or independent living aids. This decision was made because the population in need of communication, writing and computer access devices was seen to be the most underserved in past programs in the state at the time of this program's inception. We targeted the

multiply physically handicapped students for whom little programmatic or technology expertise had existed to enhance educational opportunities in the past. Mobility needs were not addressed, per se, because of the cost involved and vast population such services. The LEAs also often provide for these needs through existing relationships with private and public medical service providers. Communication, computer access and writing aids can be appropriately addressed through a statewide education agency program.

A child who is inadequately positioned cannot hope to operate an assistive device effectively; for this reason the ADC employs a Seating and Positioning Specialist, who addresses the area of device positioning, designing custom trays and switch mountings and drawing attention to certain occupational therapy principles. Fortunately, commercially available aids have improved steadily over the past several years, offering more reliable service and a greater variety of applications. Commercially-available seating systems which are modular and appropriate for our students are now much more widely in use.

The program is administered by the Central Pennsylvania Special Education Regional Resource Center. Central SERRC has an ongoing educational service delivery network of some twenty years duration. It manages a large lending library of professional materials (including software), conducts workshops and inservice training on-site throughout the state and most recently has been providing specific technical expertise and centralized laboratory style training in educational computer applications. There are 16 professional positions associated with operation of the Central SERRC. Two other Regional Resource Centers in the eastern and western parts of the state operate similar programs. All Resource Centers are funded by the Pennsylvania Department of Education, Bureau of Special Education. The ADC is a statewide program; however, it was initiated and is administered by the Central SERRC.

The Central SERRC is located in Harrisburg, the state capital. The ADC is headquartered at Elizabethtown Hospital and Rehabilitation Center, a historically pediatric rehabilitation center 15 miles away. Staff at the ADC consists of the following five professionals roles and backgrounds, with two support (clerical, secretarial) positions: a coordinator (M.S., Educational Technology), two augmentative communication specialists (CCC-speech), a positioning and seating specialist (OTR/L) and a rehabilitation engineer (M.A., Rehabilitation Engineering).

For the past six years, a high technology "Minigrant" program has been operated through the SERRCs. The Minigrant program is designed to distribute technology to special education classrooms using discretionary PL 94-142 funds. Teachers and therapists write competitive minigrant proposals delineating their need and plans for specific equipment. The grants are then processed through the appropriate SERRC for funding. During each of the past six years, $800,000.00 worth of high technology hardware and software, including classroom computers and sensory aids, were distributed by this program. The Assistive Device Center's Long Term Loan program is also a competitive program for educators throughout Pennsylvania. Administered by the ADC, this program provides assistive device systems for use by students at home and at school for as long as the devices are needed throughout the students school careers.

The Assistive Device Center was originally structured (in 1984) to support three full-time staff people serving as inservice trainers and technical advisors for therapists and teachers needing access to such expertise statewide. As educators were surveyed over time, their interest in and need for expanded services in this area became apparent. A statewide "awareness" conference in the fall of 1985 attracted the attendance of over 300 administrators and classroom personnel. The need for assistive device equipment and the necessity of ongoing training in student needs identification, equipment function and application was readily apparent. Consequently, the ADC has provided $500,000 during each of the past five years to fund this assistive device long-term loan program.

The most frequently asked questions about this program refer to insurance concerns, equipment transition (from school to work or independent living settings), and concerns about adequate student assessment and follow-up services. One unifying philosophical strand dictates the way that these concerns are addressed in the program. Cooperative relationships among agencies and students are both required and supported by the ADC program. Ultimate responsibility for the success of any technological aid system must rest with the consumer. To achieve a goal of personal control over one's individual independence, local agents come heavily into play. Over the course of the students' school career, those individual professionals involved with the student change, and even the students' educational or home settings inevitably undergo change. Thus, no one professional, agency or program can assume continuous responsibility for services, cooperation or coordination of efforts.

Consequently, the ADC loan program focuses on the individual student as the consistent, unifying agent for his/her own services. Devices are loaned, not to classrooms or to therapists, but to individual students for the duration of their need for that system, or until severance from special education services. Currently, options for funding the transition of functional equipment from school to work or independent living settings are being explored with other state and private agencies. Some creative and uniquely cost-effective strategies have been suggested.

Local educational agencies (LEAs) are required by the ADC loan program to insure equipment, and to guarantee its availability to the student at all times, including at-home use and use during vacation periods. LEAs are also encouraged to make personnel available for training offered by the ADC. These local efforts are supported by a network of Local Augmentative Specialists (approximately 90 throughout the state) appointed locally by the Directors of Special Education. In an effort to de-centralize equipment knowledge, assessment techniques and therapy ideas, the ADC provides tools and ongoing training regionally for these specialists. Since turnover is relatively high among school personnel, such ongoing training is required and will continue to be a major need even as expertise is developed by individuals. Effective follow-through services, although instigated and supported by the ADC, must be maintained by the local personnel directly involved with the student on a daily basis. This approach reduces the previous emphasis on the prescriptive phase of device application, placing such emphasis instead on the follow-through phrase.

Implications

Methods of gauging the effectiveness of this program are being devised. A recent ADC-sponsored symposium (March/87) brought academically-affiliated professionals from Pennsylvania and nearby states together to examine research issues which could be addressed, given access to the student population of the project. Among the wide-ranging issues identified were concerns with device usage, communicative competency training of users and the appropriateness of cognitive demands placed on system users. While an important part of the overall effort is to examine and improve the service offered, we practitioners must seek to involve the research community in taking an unbiased measure of the actual effectiveness of these systems and strategies, once applied. Anecdotal reports and case studies need to be joined by longitudinal research with larger subject pools. Through this program we can offer researchers access to such a group of potential subjects.

THE ASSESSMENT AND EVALUATION OF STUDENTS FOR AUGMENTATIVE COMMUNICATION SYSTEMS: THE PENNSYLVANIA MODEL

Description of the Pennsylvania Model: A Brief History

Pennsylvania is a state representing 12 million people and covering approximately 45,000 square miles. Within this population, thousands of children have been identified as having handicapping conditions that could possibly warrant ADC services. These children are educated by school districts, intermediate units or approved private schools. The ADC staff studied many of the assessment and evaluation strategies and models used by centers throughout the United States and Canada. The ADC was very impressed with the procedures of such centers as The Hugh McMillan Center, Toronto, Canada; the Communication Systems Evaluation Center, Florida; and The Assistive Device Center, Sacramento, California. However, we were concerned with the medical model that many agencies presented: a "one shot" visit approach, where the students were seen in a "center" or clinic that was unfamiliar to them and asked to perform specific tasks. In addition, valuable information from those persons knowing the student in their natural environment, such as additional family members, teachers, occupational therapists, speech pathologist, etc., was limited to written communication via a questionnaire, therapy summary report or the relating of information through the parents or the few persons able to attend the assessment with the student. With this approach, many students had to be placed on waiting lists and literally waited for months or even years for assessment and evaluation.

The ADC first attempted a modified medical model version and began to travel to a student's school to perform an assessment and evaluation procedure. This kept the student in his/her natural environment and provided the ADC staff with an opportunity to meet and discuss important questions and issues with the staff currently involved with the student. It became apparent quite quickly that this approach was inadequate. The ADC staff was travelling all over the state and was still utilizing a "one shot" visit approach. The student might be absent from school on the sched-

uled day of assessment. There were snow delays and school cancellations. The assessment procedures took longer than expected. It was an exhausting procedure for all involved.

At this time it became necessary to devise and implement a framework to support the local educational agencies and each Intermediate Unit. It was necessary to hire additional ADC staff members to provide technical and clinical support through educational training with workshops, printed materials, toll free technical hotline service, videotapes, newsletters, site visits and educational modules. A new plan of action was structured that incorporated and reinforced the basic beliefs of the ADC staff's philosophy on assessments and evaluations for assistive device systems use. The Local Augmentative Specialist Plan was developed using an educational model for assessment and evaluation.

The Local Augmentative Specialist Network

The ADC asked each of the 29 intermediate units (IU) in Pennsylvania to select three professionals from their staff to be trained as Local Augmentative Specialists (LAS). The ADC suggested that the Intermediate Units survey their staff and select professionals who appeared to be already interested in assistive devices or technology. The IUs were also encouraged to develop a "team approach" that included speech pathologist, an occupational therapist and/or a physical therapist and an educational technologist and/or teacher. Responsibilities of the Local Augmentative Specialists would be to provide local support of the long term loan program conducted by the ADC and to provide consultations for assessments of students and of equipment for students who needed augmentative and/or alternative communication.

Once the Local Augmentative Specialists were identified, the ADC surveyed the group to discover their present basic knowledge of assistive devices, their ability and/or confidence in selecting and programming devices and their readiness and ability to create educational goals and procedures for training other staff who were working with an assistive device user. All 29 Intermediate Units participated and selected staff to become Local Augmentative Specialists. Results of the ADC survey showed 34% had "some" experience with high technology, 40% had "little to no" experience and 27% felt they had "fair to good" experience. Of the group identified 46 were speech pathologists, five were administrators, eight were occupational therapists, five were physical therapists, 11 were teachers and 14 were "other." Fifty percent of the group had "little to no" experience with the majority of commercially available communication aid devices. Nineteen percent had used some of the devices before but did not understand the devices' full potential. Seventeen percent felt they understood the devices and functions of the systems very well. The educational module that the LAS selected as being most important to them would be a training module on assessment and evaluation.

LAS Training: Aspects/Equipment/Plans

First, the ADC staff selected a basic "starter" group of items and resource materials that might be beneficial to conducting an assessement of a student for an assistive device. These clinical tools were gathered in a suitcase that was called the LAS assessment kit. In addition to the clinical tools and books, the LAS kit included videotapes made by the ADC that demonstrated the basic use and programming of the most currently popular and commercially available assistive devices. Each Intermediate Unit's LAS tam was given a complete LAS assessment kit at the first LAS Training workshop.

The ADC plan for LAS training includes three major educational workshops a year for each LAS team. The ADC conducts these workshops within three geographical areas of the state: east, west and central Pennsylvania. The local specialists then attend the workshop being conducted nearest to them. Each workshop consists of a full day of educational training that includes presentations by the ADC staff members, and/or guest lecturers, technical and clinical experts in the field and/or "hands on" experiences with the actual devices, audiovisuals, tutorials, and print materials. In addition to these one day workshops, the ADC has provided opportunities for the LAS to attend segments of a graduate course in augmentative communication held at a state university and the opportunity to attend a three day ADC retreat held in conjunction with ISAAC (The International Society of Augmentative and Alternate Communication).

The ADC also provides the LAS with "on site" training during the ongoing follow-up site visits the ADC staff regularly make to students who were awarded the long term loan devices. Suggestions and training techniques are demonstrated to the LAS and the ADC staff can then consult with the LAS on any problems or situations they may currently be handling.

Short term loan of devices is provided by the ADC throughout the state to LAS. The LAS team then has the opportunity to try an actual device or system with a student before making a final suggestion or recommendation for the equipment to be purchased or applied for through an ADC Long Term Loan.

Toll Free technical hotlines operate at the ADC, Monday through Friday from 8:00 a.m. to 5:00 p.m. The LAS may use these lines for technical assistance, hardware information, technological problem solving and device programming. Concerns about seating and positioning information, symbol and vocabulary selection information, therapy implementation, problem solving and requests for site visits may also be discussed over the phone.

The LAS receive the *Assistive Device News* newsletter and are referred to other LAS from various sites in the statewide LAS Network to share similar experiences, successes and/or problems. Each LAS receives the *Augmentative Communication Profile*, a survey designed by the ADC as a tool to help therapist and teachers identify the student's strengths and weaknesses in using the present augmentative system. Once the questionnaire portion of the Augmentative Communication Profile is completed, the ADC will analyze the data and return the information with a graphed profile and suggestions for plotting efficacy of the current communication system.

In 1986–87, the main focus of the ADC training for the newly developed LAS program was to develop materials, share, and transfer information and experiences in the area of assessment and evaluation. Training materials have been developed to meet this need. The ADC produced a series of eight unique videotapes. These tapes have been distributed to over 1,000 persons and agencies in the United States and several other countries.

Efficacy and Implication of the Pennsylvania Model

Choosing a model of assessment and evaluation services that consists of training Local Augmentative Specialists has its advantages and disadvantages. Many of these advantages are quite obvious. More students may be seen and evaluated than any single team of experts could ever hope to see. Local educational agencies can continue to develop quality evaluation procedures that can directly benefit their own students. It allows flexibility and customization of a process to be more responsive to specific students, personal environments, and the current staff. It also encourages the Assistive Device Center staff to function as a resource and a support to the Local Specialists. The ADC can then provide technical support, information and provide assistance regarding specific training techniques, actual products, new products and prototypes, and current conference and research materials.

It is also hoped that this model can be more responsive to a particular student's needs and/or problems. Use of a device can be more readily instituted by local staff directly working with the student. The staff will be more invested in the student and the use of the device if they have been a part of the decision-making process from the very beginning. Problems with the device, the student or training strategies may be more quickly identified and modified, not to mention the fact that if local staff become more involved with the technology, the technology itself and its use would be more widespread.

This model also presents a wide variety of other options. Data collection and assessment of specific devices and their use is possible. Feedback from a variety and large number of clinicians is possible. A strong network of users and/or clinicians can be developed. Actual case studies could provide rich material for further study and development in the field of augmentative communication.

For this model to work, however, a Long Term Loan program is necessary. When the devices themselves can be funded and provided, local staff involvement increases. If the assessment and evaluation process have the built in component of actual possession of a device, both the student and the local staff are rewarded for their efforts. Federal government funds to states are needed to insure that these effective and necessary assistive devices are available for students with handicaps. These devices are the only method by which many disabled students can communicate orally or in writing. These communication skills are essential if these students are to be given an opportunity to maximally benefit from education programs and to participate fully in society.

Technology implementation requires our best efforts. It goes beyond the mere provision of hardware or services, to require the cooperation of many individuals over a long period of time. The benefits of technology use are readily demonstrable, however, and critically necessary for students with severe multiple handicaps.

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Mr. OWENS. Thank you.

Again, I want to thank all the panelists.

I'd like to begin with a question to my fellow New Yorkers.

Has Governor Cuomo appointed a committee, a task force, for technology for the disabled? Can you update me on what that task force or committee has done or is doing?

Ms. CARROL. I'm familiar with the Governor's task force, and have read it, but regrettably I've not seen any activity after that task force report.

Now, that doesn't mean that there isn't any activity. We will be getting in touch with our affiliates who happen to participate on it.

But to my current knowledge, there has been no follow-up that has reached service organizations at this time, and we would like to see that.

Mr. OWENS. Mr. DeWitt?

Mr. DEWITT. I can't really comment on it, because I haven't followed that particular activity.

Our center, while located in New York, tends to serve on a national basis, and we're not necessarily involved in each State's activity.

Mr. OWENS. I think that Stevie Wonder was made the chairman of it when it was first established?

Ms. CARROL. Yes.

Mr. OWENS. It seems to have faded from existence, and I have heard nothing about it since then.

Ms. CARROL. Well, we will be pursuing it.

The recommendations of the Governor's task force follow many of the discussions and are in keeping with many of the discussions here today.

We feel that they're very important, and we will be following that. We won't let it become just a heap of paper.

Mr. OWENS. Mr. Hahn, if I've heard correctly, you are the only example of a long-term loan program in existence at this point.

Do you want to describe that a little bit more? What kinds of devices do people usually get the loans for? How does this program operate?

Mr. HAHN. It operates by local educators. We feel very strongly that the local teachers and the local speech-language pathologists, the local occupational and physical therapists who work with these students and their families and the school systems need to be directly involved in that decision-making process.

We have worked hard and will continue to do so to increase those local education agency personnel's skills, and their awareness of the types of devices that are available, how to assess students for appropriate uses of devices, and then provide them with as much follow-along service as we can.

They make the determinations at the local level of what types of devices systems might be appropriate. They then get an opportunity to try that one which is thought to be the best possible device system with the student for a trial period.

They are also able to utilize a long-term loan competitive grant proposal submitted to our agency. If they are then funded, we will provide them with all the hardware, software-related types of materials, printers, paper, the whole package.

Once they've done the work to try to know what these students need, and the families and the children and the schools are excited about the possibility of this, they have some real feeling that it's going to work—there is that device at the end of that process.

Time after time in previous years we've seen other efforts where the greatest amounts of evaluations, the greatest professional minds and the greatest intentions have run against brick wall after brick wall in funding.

We said at the outset that would not be the step at which the whole thing would fall apart here. All those monies would in many ways be wasted, and the frustrations would have built again for the child, the family, and the system. We would see ourselves as a State-wide program to be able to eliminate that big barrier not totally across the whole State, but in this pilot program at the level that we were able to fund it through those discretionary funds.

This shows that with that type of appropriate funding, with the training being available to local people as to how to make these decisions, and the awareness of what the devices are and how they work, with this information and the people trained, if that money is available then the whole system can come to some fruition. Kids can actually get the devices, learn to communicate, and increase their skills.

We make devices of all types available. The only thing that we do not address are those systems that would be under $500 in cost. Our feeling is that those types of things should fall into the paper and pencil categories and schools should not have a budget busting effect to provide those students with some of the less costly types of aids.

When it gets to——

Mr. OWENS. So you will provide a loan from $500 up to what?

Mr. HAHN. There's no maximum.

Mr. OWENS. There's no maximum?

Mr. HAHN. Theoretically.

Mr. OWENS. And we've provided $500,000 a year?

Mr. HAHN. For the last three years we've spent $500,000 a year to do that.

Mr. OWENS. Thank you.

Mr. HAHN. It's an average of $3,200 per system, to give you some notion of the costs of these devices.

Again, we're working with more severely handicapped students who require typically some type of system to assist them with writing, communications, environmental types of controls or system controls, often combined with and interfaced directly with a standard microcomputer.

All those things are becoming much, much less in cost as the years go on. With our State buy type of program, we have some impact with the manufacturers and with other systems. We have high-volume purchase agreements for computer hardware. We also go out on bid, competitively, with the major manufacturers.

They've come to know that if they're providing a product that does the jobs to help schools help kids in assistive devices, there is going to be a market out there, and a source of significant amount of purchasing power, at least in this State, and we've gotten very attractive prices and substantial reductions by doing it that way.

Mr. OWENS. Thank you.

Ms. Carrol, do you want to address this?

Ms. CARROL. If I may comment to the Congressman from New York, the Pennsylvania Assistive Device Center is very well known to UCP of New York City. We're great admirers of it, and wish that there were such a service in the New York area.

Beyond our own clients that we serve, when youngsters leave United Cerebral Palsy to go into the public schools system of New York City, our judgment at this time is that they are not getting the assistive device support that they need in the school system and that the Pennsylvania model is really an excellent one. New York should look at it.

Mr. OWENS. Thank you.

While you have the mike, you mentioned regulations that were overdue. Could you just elaborate on that a bit?

Ms. CARROL. What?

Mr. OWENS. Regulations overdue from the RSA?

Ms. CARROL. In terms of the RSA, let me just—the Vocational Rehabilitation Act of 1986 in which this subcommittee had responded to testimony, and demonstrated the important impact of rehab tech services—but to date, the Rehab Services Administration has not issued regulations on these amendments, nor given States any guidance on how to carry out the amendment.

So it seems that the hearings were completed, but there's been no carryover since then.

Mr. OWENS. Again, I want to thank all of the panelists. I think that my colleague has been detained, but I'm sure that he joins me in thanking you for waiting so patiently.

I assure you that it's been a long day, but we wanted to hear quite a number of people since we haven't had such a hearing for quite some time.

I assure you that the key people who will be involved in writing this legislation are listening. [Laughter.]

They have taken into consideration all the things that have been said, and we will be responding and further developing the legislation along the lines we were informed of today.

Thank you very much, again, for coming.

Hearing is now adjourned.

[Whereupon, at 1:45 p.m., the subcommittee was adjourned, to reconvene at the call of the Chair.]

[Additional material submitted for the record follows.]

STATEMENT SUBMITTED BY THE NATIONAL EASTER SEAL SOCIETY

We are submitting this statement in connection with the hearing on assistive technology which was held on May 10, 1988. We request that these comments be included in the hearing record.

The following is intended as an overview of Easter Seal activities relating to assistive technology programs and services. Easter Seal programs are as diverse as the communities they serve. The programs described in this statement were selected to illustrate the range of technology services available through Easter Seal and common barriers encountered in the delivery of those services.

The National Easter Seal Society, founded in 1919, is the nation's oldest, nonprofit voluntary health agency providing direct services to people with disabilities. Easter Seal serves over one million people annually through 400 programs sites in all 50 states, the District of Columbia and Puerto Rico.

Easter Seals serves people of all ages and disabilities. Easter Seal programs provide a broad range of services that include physical, occupational, and speech language therapies, vocational evaluation and training, camping and recreation, psychological counseling, screening programs for potentially disabling conditions, information and referral, and family and community education. Technology assistance is an integral part of the comprehensive services provided by Easter Seal.

Service fees are based on the client's ability to pay. No one is refused services because of financial limitations. Financial support for Easter Seal programs comes from a variety of sources, including contributions from individuals and corporations, legacies, special gifts, fees, grants, contracts and bequests. Easter Seal must rely on public contributions to cover program costs for those clients who cannot pay the full costs entailed.

The National Easter Seal Society has taken a leadership role in the utilization of technology to help people with disabilities achieve the maximum independence possible. The Association for the Advancement of Rehabilitation Technology (formerly RESNA) has named the National Easter Seal Society as this year's recipient of its Leadership Award. The award recognizes the Society's "outstanding contribution and on-going leadership in the field of technology applied to needs of disabled individuals."

Nationally, Easter Seal partnerships with the private sector, information dissemination efforts and research activities have focused on the technology needs of people with disabilities. On a local level, Easter Seal affiliates provide technology assistance through a community based approach that draws on local resources and expertise. The programs involve close coordination with state agencies and community organizations.

I. PRIVATE SECTOR PARTNERSHIPS

The National Society believes that partnerships with the private sector should be encouraged and promoted. We have been involved in a number of cooperative ventures with the private sector over the years.

Some of the benefits resulting from these projects include (1) an increase in the number of people with disabilities having access to assistive devices; and, (2) an opportunity for the private sector firms to highlight their corporate commitment to people with disabilities and to heighten public awareness of the adaptive technologies available to them. An increase in public awareness helps to strengthen market demand for these products.

Easter Seal/IBM assistive technology project

In September 1987, Easter Seals and IBM announced the IBM Offering for Persons with Disabilities. The joint project was created to provide computer products and assistive devices to people with disabilities at discount prices. The National

Easter Seal Society was selected as the community service organization for this offering.

To become eligible for the program, the individual must submit a letter from a licensed physician stating that the individual has a disability and would receive therapeutic or rehabilitative benefit through the use of one or more of the products available in the offering.

The letter of certification is sent to the nearest Assistive Technology Center. These centers are operated by East Seal affiliates. There are currently ten centers located in Arkansas, California, Colorado, Florida, Georgia, Illinois, New Jersey, Rhode Island, Texas and Utah. IBM donated equipment for the centers and provided training programs for the staffs.

Each Assistive Technology Center provides the following services:

(1) hands-on demonstration and evaluation of available products;

(2) assistance in choosing products, calculating payment and filling out the appropriate order forms;

(3) receipt, assembly and testing of systems to ensure that products are operational prior to delivery to the end user;

(4) discussion of warranty and maintenance options available to end user and procedures for obtaining them;

(5) hardware set-up assistance and initial training; and,

(6) telephone support for on-going assistance once the system has been delivered to the end user.

The equipment is available for purchase at a 33-50% discount.

Despite the significant savings provided through the IBM Offering, financing equipment purchases is very difficult for eligible individuals. Even with the discount, the equipment costs range from about $300 to $2,000. To date, there are no programs that would provide low interest, variable term loans to people with disabilities for the purpose of obtaining assistive technologies and related services.

Financial institutions are reluctant to finance equipment purchases and are not likely to approve loan applications from individuals who do not have an established credit rating. Requiring a lump sum payment for equipment places a financial burden on those with limited resources.

Exploring reimbursement sources for assistive technology devices requires a significant commitment of staff time and effort. For example, the New Jersey Easter Seal Society operates an Assistive Technology Center that serves New Jersey, New York, Connecticut and the mid-atlantic region.

There is one person on staff to provide technical support to consumers. Part of the technical support involves sorting through reimbursement policies for state vocational rehabilitation agencies, Medicaid programs, private insurers and other third party payors. The staff currently deals with over 21 different Medicaid policies. Another problem is reluctance on the part of some state agencies to pay the state tax required for purchase of the IBM equipment.

Unless creative solutions are found to help with the financing of equipment purchases, the market will continue to be limited to those who can afford lump sum payments or those who have found a charity or other source willing to assume out-of-pocket costs for the equipment.

Other private sector initiatives

Five years ago, Apple Computers donated 400 used computers to the National Easter Seal Society. Apple provided $35,000 to test the computers, which were refurbished and made available to Easter Seal affiliates.

The New Jersey Easter Seal Society uses the Apple computers in training centers for people with developmental disabilities. Individualized computer programs have been created that correspond with the person's Individual Habilitation Plan.

AT&T provided $10,000 to underwrite an issue to COMPUTER DISABILITY NEWS. The newletter is published by the National Easter Seal Society and is widely read by special educators and service providers interested in assistive technology. Newsletters and other publications are a major source of technology assistance to both consumers and service providers.

II. COMMUNITY BASED PROGRAMS

The National Easter Seal Society believes that community based service delivery is an effective approach for meeting the needs of people with disabilities. Easter Seal programs provide technical assistance to underserved populations in rural as well as urban settings. A critical component of the community based approach involves cooperative agreements and service coordination with state social service and local education agencies.

Serving the rural community

There are over 8.5 million people with disabilities in rural areas, including approximately 560,000 farmers and agricultural workers. Currently, there are three major programs in the United States that specialize in rural rehabilitation technology: the Rural and Farm Family Vocational Rehabilitation Program in Vermont, Breaking New Ground at Purdue University in Indiana, and the Iowa Easter Seal Society's Farm Family Rehabilitation Management Program (FaRM).

The Iowa FaRM program has been a pioneer in the community based approach to rural rehabilitation technologies. The program director travels many miles across the state to provide on-site agricultural worksite modifications and consultations. Other program features include coordination of independent living and community services, use of community resources in the design and fabrication of adaptive devices, peer support services, and ongoing communications between the family and health care providers.

The program director is currently carrying a case load of over 140 families. Additional resources will be critical to the future of the program. Funds for staff training are essential due to the specialized training needed to effectively serve farm families. Without additional trained staff, it will be nearly impossible for the program to expand at its present rate.

Coordination with State agencies

The Texas Easter Seal Society recently purchased a driving simulator that is used to test reaction time and responses to complex situations of individuals with traumatic head injuries. The simulator was purchased at a cost of $37,000. It took a year and a half to raise funds for the purchase.

The Texas Rehabilitation Commission, after learning of the availability of the simulator, has begun referring clients to the Texas Easter Seals for testing and evaluation. Individuals involved in state programs for the aging are also being referred. Testing and evaluation are conducted on a fee-for-service basis.

The Texas Easter Seal Society will recover the cost of the simulator within three years. The state agencies have avoided costly purchases by coordinating services with Easter Seals. In order to meet the rehabilitation technology needs of other Texas residents with disabilities, the Texas Easter Seal Society will need to raise an additional $360,000 for equipment purchases. Flexible, long-term financing programs would help expedite the process of buying this equipment.

III. INFORMATION DISSEMINATION

A major barrier to service delivery is a lack of information and awareness of assistive technology services. This is particularly true for rural areas. The National Society strongly supports efforts to coordinate and disseminate information on assistive technology services for both consumers and service providers. We continue to promote research in this area.

Rehabilitation Technology Volunteer Census Project

The Easter Seal Research Foundation, established in 1956, is the research arm of the National Easter Seal Society. Grants funded by the Foundation support research relating to the development and use of technology.

The Foundation recently awarded a grant to identify voluntary groups working in the field of rehabilitation technology. The nationwide study will provide a census of groups and individuals working on a volunteer basis and will consider ways in which the volunteers can help each other. This research is providing the first step in establishing a nationwide network for sharing resources and designs that would benefit people with disabilities.

Jim Tobias, founder of the Rehabilitation Engineering Volunteer Network, is directing the project. Following completion of the census next year, some long-term goals for the project include:

Creation of a "design file" that would contain information on completed projects to encourage problem solving and information sharing among engineers.

Establishment of a center for collecting and storing surplus equipment that could be made available at a discount to people with disabilities.

Development of a program for resource sharing of training materials developed by various groups involved in the delivery of assistive technology services.

Additional funding would be needed before these and other ideas could be developed. However, the initial study will provide a research base for developing technology information and referral systems on both national and local levels.

IV. OTHER CONSIDERATIONS

The National Society believes that a system for technology assistance should provide for successful transitions throughout the lives of people with disabilities. This requires an increase in funding commitment for specialized training of personnel, and policies for developing professional standards for service delivery. Reimbursement policies must be studied to determine priorities for funding technology assistance, to ensure that individuals are reimbursed as they make the transition from one system to another, and to ensure that individuals defined as handicapped or disabled under federal or state law are reimbursed for technology assistance that enables them to achieve life activities. Barriers to service delivery must be identified and eliminated.

For example, the New Hampshire-Vermont Easter Seal Foundation is finding that private insurers are routinely denying reimbursement of services to individuals with developmental disabilities. The insurers refuse to pay for services that they claim are "habilitative" rather than "rehabilitative."

Some youths with disabilities require vocational training while in school. In many cases, students are not reimbursed for equipment purchases unless it is written into their IEP. Some of the school districts are reluctant to fund equipment that they consider to be "work related." The state vocational rehabilitation agency will not fund equipment for individuals who are still enrolled in school. Furthermore, many vocational rehabilitation agencies are reluctant to use limited funds for purchasing equipment for their own clients.

V. SUMMARY OF RECOMMENDATIONS

Based on our experience in providing assistive technology services, we recommend that assistive technology legislation should:

(1) adopt a broad definition of assistive technology that includes related services involved in making an assistive device available to people with disabilities (e.g., information and referral, evaluation, training, technical support, maintenance and upgrading of equipment)

(2) require that states conduct statewide surveys of existing programs—both public and private—and use part of the available funds to enhance these programs (this will ensure that the number of people receiving direct services will increase at the same time that states are building their capacity for a statewide assistive technology delivery system)

(3) encourage a community based approach to service delivery with citizen/family involvement in the development of services

(4) encourage the development of public/private partneships

(5) establish a funding commission to study existing reimbursement sources and develop programs for financing adaptive equipment and services

(6) mandate a short-term study to develop a national program for meeting the technology information needs of consumers and providers

(7) provide for a comprehensive system for personnel training

(8) address technology needs of individuals receiving transition services

(9) develop a state grant program that would encourage the development of model programs and coordination of services

We recommend Chairman Owens for addressing this critical issue and appreciate the opportunity to submit this statement for the record.

STATEMENT OF THE COUNCIL FOR EXCEPTIONAL CHILDREN AND THE TECHNOLOGY AND MEDIA DIVISION

Mr. Chairman, the following statement is presented on behalf of The Council for Exceptional Children (CEC) and its Technology and Media Division (TAM). The Council for Exceptional Children is the international association of professionals and others involved in and concerned about the education of students with handicaps as well as students who are gifted and talented. TAM is an organization of CEC members devoted to the improvement of research, development, training, and demonstration activities related to the application of technology to exceptional individuals.

We believe that technology can be a powerful tool for improving the quality of life for all people, but most especially those with handicaps. We commend Congress for recognizing the importance of technology over the years. One hundred nine years ago, Congress authorized the establishment of the American Printing House for the

Blind, which has been devoted to bringing the technology of the day to sightless persons throughout the nation.

Over the years, efforts of the Library of Congress, the Department of Education in rehabilitation and education, the Veteran's Administration and others have played a major role in advancing technology applications. We particularly want to commend the Congress for the new legislative authority created in 1986, part G of P.L. 99-457, and we hope that with some modest funding, better educational technology can be developed and made available.

We believe that it is time to take a major step forward. The age of electronic technology has created an opportunity to dramatically improve the lives of persons with handicaps of all ages. We believe that our society cannot afford to miss the opportunity to assure that such persons have access to appropriate technology assistance. While we recognize that there are wide ranges of issues that need to be addressed, we will focus our comments on educational applications. But we want to convey our support for a more comprehensive view as legislation is developed. Our statement addresses two major issues. First, we will present ways technology assistance can significantly improve educational opportunities for persons with handicaps. In this regard, we strongly believe that education is a lifelong process and that while our examples will focus on children and youth, application, should address persons of all ages. Second, we will propose basic principles that any legislation developed should address.

Using Technology To Improve Educational Opportunities for Persons With Handicaps

Improved educational opportunities have accrued for persons with handicaps through the application of technology to improve their ability to: (a) learn, (b) actively participate in an education environment, and (c) apply newly learned information across environments.

(A) TECHNOLOGY AS A LEARNING TOOL

As a tool to improve the learning of persons with handicaps, technology is an exciting and inescapable feature of modern life. It is becoming a more accessible and integral part of teaching handicapped persons. According to Budoff, Thormann, and Gras (1984), the advantages of using technology to teach persons with handicaps include:

(1) Individualization and self-pacing: With well-programmed Computer Assisted Instruction (CAI), students work at their own pace with material that meets their specific needs. In addition, rate of presentation and response may be regulated for each student.

(2) Immediate feedback: Students receive immediate feedback about their performance.

(3) Consistent correction procedures: Students with handicaps are often confused by corrections that are too wordy. CAI can provide specific, consistent correction of errors.

(4) Repetition without pressure: Since the computer is emotionless and infinitely patient, repetitive tasks may not be aversive or embarrassing for the student, but indicative of mastery. This is particularly important for slow-learning students who do not experience success in academic tasks frequently or easily.

(5) Immediate reinforcement for correct responses: The software provides immediate positive reinforcement for correct answers, which motivates students.

(6) Well-sequenced instruction: A task may be analyzed, broken down into manageable steps, and then programmed. Special education teachers often do not have the training or time to construct the consistent, well-sequenced instruction that most handicapped students need, and that good software can provide.

(7) High frequency of student response: If the interactive features of the computer are put to full use, students get more practice solving problems than they do working in large groups or with work sheets.

(8) Repeated demonstration of mastery of academic subject matter: A sense of mastery of subject matter, especially academic subject matter, is very important to students who have experienced and continue to experience failure in instruction. The computer allows them to review their earlier attainments and recall them. The students can demonstrate to themselves and others their competence in academic subjects. These ego boosts can be critical at times of frustration. The special education student can be "in control of" his learning.

(9) Motivation: This can be described at two levels. Many students with handicaps are excited by working on a computer, even doing class work. For others, it is an

excellent motivator to allow time for computer games as a reward for work completed. Earning computer time may result in more focused and concentrated work by easily frustrated students who produce slowly or not at all in their usual assignments.

(10) Minimize disabilities: The computer enables the poor or inefficient learner to minimize or circumvent significant barriers to learning. Students who are able to understand basic math concepts but unable to do error-free calculations (due to poor memory, visual, perceptual, or other problems) can manipulate numbers and letters with greater ease and accuracy in an interactive mode. Their reasoning abilities can be expressed without interference from their problems in producing output. Using the computer as a work processor may help a special education student bypass writing, spelling, and language arts problems by allowing the student to edit and revise work easily. The time and energy formerly spent on laborious rewriting of rough drafts can be spent developing ideas in a legible and acceptable form. The ready availability of spelling or punctuation checking programs can pit the child against himself. The computer motivates him to reduce spelling or other writing errors, since he can chart his errors after each attempt to reduce them. Most important, the child unable to produce acceptable work can demonstrate his productivity to himself and others.

A substantial amount of information is available documenting the positive effects of technology on the learning of persons with handicaps (Behrmann, 1984; Budoff, Thorman & Gras, 1984; Cain & Taber, 1988; Carmen & Kosberg, 1982; Cartwright & Hall, 1974; Goldbert, 1979; Hartley, 1977; Hasselbring, 1982; Haus, 1983; Jamison, Suppes, & Wlls, 1974; Kulik, Bangert, & Williams, 1983; Rieth & Polsgrove, 1983). In addition to the professional literature, there are personal vignettes I would like to share that poignantly illustrate the power of technology to improve the learning, self concept and motivation of persons with handicaps.

A group of high school students with mental retardation enrolled in an inner city high school in Indianapolis, Indiana who, despite being classified as 10th, 11th and 12th graders, had achievement levels between 2nd and 3rd grade level. Most of the students has long histories of school failure despite their assignment to special education programs. Many attended school only about 50% of the time. Early in the school year they were provided a modified learning and instructional program that included computer-based instruction to assist students in learning basic math facts, basic reading skills and spelling skills. We also used computer games to motivate students to accurately complete paper and pencil assignments. Within one month, all the students were attending school, every day and were not cutting classes. Within two months, the students were submitting all assignments on time and were not failing any subjects. By the end of the year, the students had increased their achievement in math and reading an average of 2.5 grade levels and none of the students dropped out. Students who remained in the program for a second year also increased their achievement an additional 2.5 grade levels. Thus, in two years, the students had tripled their rates of achievement due to excellent teaching, good instructional and behavioral management strategies, and the use of computers.

Another study included 20 high school students with handicaps who were unable to learn basic addition, subtraction, multiplication, and division facts. Many of these students had been working on the same facts since third grade. By this time, they had resigned themselves to failure and showed very little interest in continuing to work on this material. The average student completed about 20 math problems every half-hour. Once computer-based math drill and practice began, the students increased their work speed to an average of 10 problems correct per minute. After four weeks of starting computer-based instruction, the students standardized math achievement test scores increased an average of two full grade levels.

Recently, computers were used to teach a group of 40 junior high school students with learning disabilities from the Metropolitan Nashville, Tennessee Schools who had great difficulty learning basic math operations. Computer games were made accessible based on meeting negotiated performance criteria. Tommy, made rapid progress and was elated with his achievement. When asked what he liked best about working with the computer, he responded with a wide grin and said, "it makes me feel like a genius".

These vignettes highlight the power of technology to transform the lives of persons with handicaps. In addition, there is substantial research to support the impact of technology on the learning of students with handicaps. In this next section, we will briefly review information highlighting the effectiveness of technology to enable students with handicaps to increase their rate of learning.

Knowledge base

Microcomputers have been used in special education for the past nine years and research indicates that the number of computers being placed in special education classes is rapidly increasing (Becker, 1986; Cosden & Semmel, 1987). By far, the most common use of the microcomputer in special education is to develop proficiency in the basic academic skills of math, reading, spelling, and writing (Becker, 1986; Cosden & Semmel, 1987; Okolo, Rieth, & Bahr, in press; Rieth, Bahr, Polsgrove, Okolo, & Eckert, 1987; Russell, 1986). Experts, such as Lesgold (1983) and Torgesen (1984), believe that drill and practice is required to enable children with handicaps to attain fluency in basic academic skills. They argue that special education students do poorly in reading and math because they may have failed to master basic skills. Making these basic skills fluent and automatic requires extensive practice for which the microcomputer is ideally suited.

Math

For years, educators have argued that, in order to fluently recall math facts, students must be provided with many opportunities to practice these facts. More recently, the computer has emerged as one way of providing students with large amounts of extended practice (Gagne, 1983). Virtually all of the studies investigating the efficacy of math drill and practice software have found that fluency has increased on the problems that the students practiced. Trifiletti, Frith, and Armstrong (1984) analyzed the effects of math drill plus tutoring on a group of students with handicaps proficiency with unknown math facts. They found that 40 minutes of computerized tutoring plus drill per day was more than twice as effective as an equivalent amount of teacher delivered math instruction. Hasselbring, Goin, and Bransford (1987) examined the effect of tutoring plus drill on the math performance of a group of 150 students with learning disabilities. They reported that after only 49 days of instruction on math software, a computer instruction group increased the number of facts recalled by 73% over their pretest score. During the same period, a non-computer contrast group showed no change on the number of facts that they could recall from memory. Kelly, Carnine, Gersten, and Grossen (1986) examined the efficacy of using a videodisc to tech fractions to a group of high school students with mild handicaps. They concluded that the videodisc was an effective teaching tool that can be used to demonstrate concepts clearly and is substantially less labor intensive than teacher-based instruction.

Reading

There is growing consensus that the primary reading difficulty experienced by students with mild handicaps is at the word, rather than the text level of processing. Thus, students with mild handicaps require instruction designed to increase fluent and efficient word recognition. Jones and Torgesen (1987) found that computer-based instruction enabled students to increase their reading speed by 26% versus a 4% increase for students taught by teacher-based instruction. The computer-based instructional group increased their accuracy by 20% while the teacher-based instructional group demonstrated only a 5% increase. Johnson, Carnine, and Gersten (1986) reported that computer-based instruction was an effective method of efficiently and effectively teaching reading vocabulary. Jones, Torgesen, and Sexton (1987) used a computer-based reading program for 15 minutes per day over a ten week period to teach reading skills to a group of students with handicaps. They found that it resulted in a 27% increase in reading speed. More impressively, the students receiving the computer practice showed a simultaneous 20% increase in accuracy on a generalized word list that was never practiced during the training. Roth and Beck (1984) examined the effect of computer-based practice on reading decoding and found that students using computers increased their reading speed by 17% while a contrast group who did not receive computer instruction produced only a 3% increase in their reading speed. Similarly, Spring and Erry (in press) reported that well designed computer-based training of reading decoding skills increased the fluency of students with mild handicaps.

Spelling

Teague, Wilson, and Teague (1984) worked with a group of young students with mild handicaps to compare the efficacy of computer-based spelling instruction with traditional spelling instruction. The results indicated that the students made significantly more improvement when computer-based instruction was used. In a series of studies, Hasselbring (1982, 1984) reported that "voice presentation" of words via computer in combination with imitation plus modeling feedback was successful in developing high levels of spelling accuracy by such students. It was also found that this approach was significantly better than traditional spelling instruction. Rieth,

Bahr, McCarthy, & Polsgrove (in preparation) used a computer linked DEC TALK coupled with a distributed practice study procedure to increase the weekly spelling test scores attained by a group of 15 students with handicaps by 40% over pretest scores.

Writing

Morocco and Neuman (1987) conducted a two year observation study investigating the use of word processors to teach writing to learners with mild handicaps. They concluded that procedural writing instruction coupled with computer instruction was the most successful technique for teaching writing to these learners.

Ellis (1986) compared student writing under three conditions: (a) handwriting, (b) work processor, and (c) word processor plus idea processor (outlining program). Following strategy training, the students' writing improved under all three conditions with the word processor showing the best results.

Problem solving

Maddux (1984), Schiffman, Tobin, and Buchanan (1982), Russell (1986) have suggested that the computer is a powerful tool for the development of thinking and problem solving in students with learning disabilities. Probably the most publicized way of developing problem solving skills has been through the use of interactive programming languages, the most prominent being LOGO. Turkel and Podell (1984) used LOGO Turtle Graphics to teach thinking and problem-solving to eight students with mild handicaps. Students employed mathematical concepts such as estimation of distances, angles, plotting points on a grid, spatial awareness, and sequencing. Also, students had to find and correct errors in programs. They found that the students were generally focused, systematic in their problem-solving behavior, organized, on-task, logical, and they appeared motivated. Woodward, Carnine, and Collins (1986) used simulations to teach health-related problem-solving skills. They reported that the simulation group was superior to the conventional group on measures of problem solving in the areas of disagnosing health problems, prioritizing them regarding their effects on a person's longevity, and prescribing appropriate remedies. Collins, Carnine and Gersten (1987) reported good success in using computer-based instruction to teach high school students with handicaps to draw conclusions from two statements of evidence and to determine whether a two statement argument was logical. Despite the evidence that technology is effective in assisting these students to learn, there is additional research and development that must be done to increase our knowledge of how to most effectively use this powerful tool. Simultaneously, we must strive to develop new and more sophisticated applications to assist persons with handicaps. In the following section, I will briefly highlight some of the more pressing needs for additional research and development.

Research and development needs

Despite the ready availability and the efficacy of computers as teaching and learning tools, many teachers are not using computers to teach students with handicaps (Rieth et al., 1987). Research must investigate factors such as the lack of educationally sound software, logistical problems in scheduling microcomputer use, and the lack of teachers training and support that contribute to the limit use. We must conduct additional research to determine the conditions which facilitate the widespread adoption and diffusion of technology among special educators. Teachers still primarily use computers for math, reading, spelling, and writing instruction. Therefore, further studies are needed to identify additional applications in these areas as well as the areas of science and social studies. We need to know more about the instructional features of software that will influence student learning. Given the finite resources available to purchase additional machines, we must learn whether students can be grouped for computer-based instruction, how the groups should be composed and how student performance while working in groups should be evaluated. In the area of problem solving we have just begun to develop a knowledge base that will guide important research.

(B) TECHNOLOGY TO IMPROVE FUNCTIONING IN EDUCATIONAL ENVIRONMENTS

Technology is also a tool that can be used to make the learning environment more accessible and enhance individual productivity. Computer technology as a tool for children to access educational environments can be divided into four general categories; 1) a learning (academic) tool, 2) a living tool, 3) a vocational tool, and 4) a recreational tool.

The computer as a learning (academic) tool

As described earlier, computers are powerful instructional tools. To use the tools, one must be able to access the environment. For example, technology can facilitate access. Students with handicaps can use telecommunications to access essential learning information. Wheelchairs are now equipped with microprocessors enabling persons with handicaps greater access to schools. Communication devices enable students, heretofore unable to communicate in school, to interact with teachers and their peers. Spoken text allows individuals with visual handicaps or those with severe reading deficits to use word processing.

The computer as a living tool

Computers can facilitate daily living activities in a broad array of environments. For children with multiple handicaps, the computer can be used to manipulate the environment by controlling tape recorders, electrical appliances and robots capable of manipulating food and drink. Voice synthesizers and communication software packages allow non-verbal children to talk to teachers and peers. Children with visual impairments can read written material with optical scanners and synthesizers as well as access electronic media such as electonic encyclopedias. Children with handicaps can interact with other children using telecommunications. Word processing, spread sheets, and database productivity tools can assist in communication, solving math problems, learning to balance a checkbook and home living skills (e.g., retrieving recipes).

The computer as a vocational tool

Computers are being used extensively in schools to prepare students for future vocational settings. Our society is changing from an industrial base to an information base. Cottage industries specializing in information manipulation are increasing in number and the manufacturing industry is rapidly developing a technological base. Technology allows persons with handicaps to participate in this transformation.

Just as technology can be adapted to allow most students to use a word processor to satisfy academic and communication needs in school, it can also be adapted to provide access to learning vocational applications. Technology manufacturers such as Apply and IBM include design parameters in new equipment that ensure that individuals with a disability can utilize standardized interfaces. Robitic workstations have been developed at such companies as Boeing Industries to enable quadriplegic employees to continue with their jobs. For individuals who are difficult to integrate into the work setting, telecommunication offers an option of working at home or in a smaller cottage industry better suited to meet the needs of individuals with a disability. Services such as mailing lists, data buses, etc. can be maintained by children and youth who have the capability of learning the skills necessary to be productive yet need special medical or other assistance.

Computers as recreation and leisure tools

Play, recreation, and leisure are important parts of the learning process and technology can provide more normalized access to these activities. For example, socialization is enhanced through telecommunications. Auto dialers can easily contact friends and augmentative communication devices can support direct one to one interactions. Graphics packages for drawing and color printers to make hard copy allow access to art. This software can be accessed using adapted devices allowing a child who cannot hold a crayon or a child with limited cognitive ability or perceptual motor dysfunctions to express themselves by drawing. Synthesizers can enable a child unable to use a piano keyboard to compose music and explore music and sound. Popular video games such as "Super Mario Brothers" and "Pac Man" become accessible with adapted devices and electronic control over the speed of the computer.

Empowering students through technology

In order to enable children with handicaps to utilize these new and powerful tools to access educational opportunities it is necessary to provide appropriate training and easy access to technolgy. For students with handicaps, particularly those with higher cognitive functioning, we need to emphasize access to systems in our educational environments, with the primary emphasis on allowing them to utilize minimally adapted commercially available computer hardware and software.

The following vignette is presented to illustrate technology's capacity to foster environmental access. Michael is a wheelchair-bound nine year old with cerebral palsy. He is quadriplegic and has physiologically inadequate speech production mechanisms. In spite of these physical impairments, Michael's parents and teachers

were convinced of his cognitive potential. Their faith in his ability has proved to be well founded. For the past six months Michael has been using a microelectric augmentative communication system with synthesized voice and printed output. Until he had access to this technology, Michael could not "talk," write, or read. Now with the help of a simple word processing system and a complex message system, he can do all three. In the past, Michael was disenfranchised and largely disengaged at school. Now he is engaged in communication, language, and literacy learning. He has learned to use his schools electronic mail and bulletin board system to send messages to other students and others. And, for the past month, Michael has enjoyed communication with Linda, who like Michael, recently moved from a beach community on Cape Cod to the Great Plains. Linda, who has a hearing impairment, and Michael love to reminisce, and they have both learned to write about sand dunes, surf at high tide, and lobster tails. In fact, they have co-authored an essay, "Surf and Sand," for their schools desktop publication, *Essays About Our Country*.

Knowledge base

Taber (1984) identified five significant freedoms which would accrue to individuals with special needs through the effective use of technology. These include the efficient and effective use of time, the enhancement of learning processes and outcomes, greater environmental independence, and meaningful involvement in gainful employment. Such primary achievements can be expected from the judicious applications of technology on behalf of those with special needs, and each relate directly to the enhancement of communication—Taber's fifth freedom.

Access to academics

Gregg Vanderheiden, in his article "Computers Can Play a Dual Role for Disabled Individuals" (**BYTE**, September, 1982) suggested: "... the immediate future promises to be an extremely exciting and productive period, which will see rapid advances in the development of both special function programs and new strategies to ensure the complete access to disabled individuals to the world of microcomputers."

If this access can be assured, then the functional disabilities currently experienced by these individuals should decrease markedly as our society moves more and more into the electronic information age. If we fail to ensure access to our computer and information-processing systems for individuals with handicaps our progress into the electronic information age will only present new barriers.

Access to living skills

Communication is perhaps the single most important access in educational environments. Communication is required for interacting in the classroom. Voice synthesizers allow the nonverbal person greater access to active learning opportunities by providing opportunities to interact.

Before electronic and computer technologies, the written and oral communication of students with severe handicaps was mostly limited to pointing, head shaking, and eye gazing. Interpreters would express in their own words what they thought the student intended. Now computers enable nonverbal individuals to more clearly express their thoughts through written and spoken language.

Appropriate software can enable persons with handicaps to gain control of TV, VCRs, stereos and lights. Training for environmental control can begin at an early age with the use of devices that control battery operated toys such as the Omnibox (Lahm & Behrmann, 1986). New research and development in the field of robotics has generated excitement in the field of special education. For example, robotic arms, controlled by an individual can peform routine daily tasks such as feeding, magazine reading and telephoning.

Access to vocational activities

Microcomputers are being used in the vocational training curriculum and are benefiting persons with handicaps by: (a) bringing assistance to individuals for less cost, (b) allowing access to information available to non-handicapped peers, and (c) developing intelligent prostheses that help off-set the information processing problems of the student (Vanderheiden, 1983). Speech recognition is an example of improved access (Rizer & Hiner, 1985). While many adults with handicaps have some keyboard skills through the use of single fingers or head pointers, the process is long, tiresome, and difficult to execute simultaneous key presses such as shift-A for capitalization. Transparent speech recognition systems allow concurrent keyboard and voice entry for virtually all software programs giving the person who is severely motorically handicapped, but verbal, access to all software and electronic information typically available to non-handicapped persons.

Rehabilitation centers have typically employed four job training approaches. They include (a) computer learning for information access and general office job skills, (b) specialized environments for computer programmers, (c) specialized equipment as sensory aids, and (d) soft-based assessment and training. The first approach was used by Holleman (1986) to train college students with disability on standard computer software for personal and job use. A computer learning center was established through continuing education that has adopted an open entry/open exist policy. This allowed the students to learn at their own pace on a schedule that meets their needs. Assistants, adaptive equipment (e.g. braillers, voce synthesizers) and sign interpreters are always available to make the technology accessible. Skills learned can be transferred directly to a number of jobs and will enable students to continue to access new information through the computer.

The University of Maine at Orono has established a rehabilitation project in data processing to train students with disability to become business applications computer programmers (White & Cormier, 1986). To achieve their goal, they have simulated a business-like environment to conduct their training. Although the costs are high, they have found the project to be cost effective.

Access to play and recreation

Play is believed to encourage intellectual, physical, and social growth. Play adaptations, specific skill training, and environmental modifications have been suggested as ways to enhance the leisure activities of children with handicaps (Haring, 1985; Murphy, Carr & Calias, 1986 Nietupski, Hamre-Nietupski, & Ayres, 1984). It is apparent, however, that current advances in technology may also assist youngsters with special needs to participate in recreational activities. Such advances include the use of communication enhancement devices, prosthetic devices, and electronic toys and robots.

Considering the impact that electronic technology is having on our entire society, it is not surprising that a similar effect is seen in the use of toys. Many electronic toys are based on recent advances in computerization. Steven Kanor is an engineer who has spent many years adapting commercially available toys to meet the operating needs of children with handicaps. His adaptations are based on each child's movement capabilities which are matched to electro-mechanical switches. After identifying the movement that is most appropriate for the youngster, Kanor designs a switch which can control a variety of adapted toys or other electronic devices. Available switches include those that are controlled by touch, light, voice, movement, position, and other stimuli.

(C) USING TECHNOLOGY TO TRANSFER SKILLS TO NEW SETTINGS

Technology can promote the transfer of new skills to related skills and to new settings. Generalization refers to the number of content areas, behavior, and situations affected by the initial instruction (Keogh & Glover, 1980). Methods for achieving generalization have been defined and are considered critical for eduation (Stokes & Baer, 1977). This section will illustrate ways that technology can serve as a tool for generalization and report research findings related to this topic.

Technology as a tool for generalization across settings

The goal of education is for skills initially learned in one context (e.g. classroom) to be used in many different contexts (e.g. home, community, employment, recreational settings). One way to reach this goal is to provide technology assistance to the students in these non-school environments. For example, a student with physical disabilities learns to use word processing in a language arts class. This same student can use word processing skills at home for personal correspondence, to obtain a job, or for creative writing as a leisure skill. These outcomes are promised on the availability of a computer system where the person lives and works. Newly learned skills would be more likely to transfer to different settings because of the technology which becomes a common tool for the pursuit of various goals.

Technology as a tool for generalization across skills

An illustration of how technology can serve as a tool for generalization can be seen, for example with a student named Billy. Billy is presently enrolled in a regular third grade classroom with resource room instruction for his core academics. He is ten years old with physical disabilities which primarily affect his ability to write. He also has poor vision and requires large print books. Before the introduction of technology, Billy as a non-reader and his writing attempts were illegible. After training in the use of a computer and a word processing program, Billy completes

class assignments and generates creative stories. Many aspects of his learning have improved as a function of his newly acquired word processing skills, such as his reading skills which have improved to the second grade level (LeFave-Ferrara, 1988).

Knowledge base

Working with infants and young children, Behrmann and Lahm (1983) have shown that microcomputers can provide infants having limited motor abilities with the consistent control of their environment necessary for normal concept development. These researchers suggest that this environmental control should, in turn, affect language, self-concept development, communication, and social interactions. Kehr, Morrison, and Howard (1986) provided technology assistance to young children who were so physically limited that they could not play with conventional toys. By programming board games into software that is single switch activated and has synthesized speech, the children became independent in play, had increased opportunities to socialize, and also could accurately indicate their choices within that play. Improved self-esteem, mastery of part of the environment, and opportunities to develop cognitive and social skills were the major benefits achieved through computer use with those children. Other positive side effects of computer use with preschoolers has been interaction with their non-handicapped peers. Dickson (1986) found computers to be two or three times more effective at encouraging social interaction than more traditional social activities, such as snack time and playacting.

Trachtman (1984) reports that Drs. Meyers and Rosegrant used the speech synthesis capabilities of the computer in language training and found that many children who began to speak through the computer's voice rapidly started speaking themselves. This spontaneous language was not a direct goal of the program but represented the gains sometimes seen when young children are introduced to this medium.

Generalized effects have also been observed with respect to academic skills. Chiang (1986) reported transfer effects of microcomputer drills on the multiplication skills of students with learning disabilities to conventional paper and pencil tasks. Gains were significant after only a short period (i.e. 12 days) of computer use.

Two types of generalization were illustrated in the research of Farr, Hummel, Jadd, and Stein (1985). They developed a communications prothesis consisting of a morse writer system for an eight year old child with spastic quadriplegia. Generalization across skills was observed from the child's reading program to his spelling program. Generalization across settings was observed among school, home, and private therapy environments. Beneficial effects of computers that spread across related skills were also observed in participants of the Comprehensive Training and Employment Project in Hawaii (Peet, 1985). This project is an example of a post-secondary program which provided technology assistance to persons with developmental disabilities. In addition to learning to master business level word processing, the program participants learned decoding skills (reading texts they word processed) and encoding written language (creating and printing texts).

In addition to increasing skills, the computer has been shown to have a positive effect on the reduction of behavior that interferes with learning. Plienis and Romanczyk (1985) conducted a comparison study of instruction delivered by adults and instruction delivered by the computer to teach a discrimination task to severely disturbed children. These researchers found that both methods were equally effective with respect to learning the task. However, the children exhibited more deviant behavior when the adult provided the instruction. Thus, a positive side effect of the computer instruction was a reduction in levels of disruptive and self-stimulatory behaviors.

A similar effect was observed by Lewis, Nail, Henschel, and Panyan (1988) who found that the use of a communication system consisting of a microcomputer, speech synthesizer, and touch tablet resulted in fewer inappropriate behaviors than the use of a language board alone. The training objective was to increase communication which was facilitated by use of the microcomputer system. Inappropriate behaviors were monitored but not directly treated in this study. Thus the improvements in the behavior can be viewed as generalization across skills as a result of the communication training with the computer system.

In conclusion, various forms of generalization have been observed in studies of technology applications in special education. Many studies report gains and growth beyond the skill(s) which was a direct focus of the investigation. By far, the consistent finding across ages was improved self-esteem (Kehr, Morrison, & Howard, 1986; Peet, 1985). Other authors have commented on the heightened motivation associated with using the computer for learning (Thorman, Gersten, Moore, & Mornat, 1986;

Trachtman, 1984). Future technology applications should incorporate provisions for generalization across skills and settings so that even more efficient and effective learning may occur.

Basic Principles for Legislation

1. CEC and TAM would like to offer the following principles which we believe should guide the development of comprehensive legislation in the area of technology for persons with handicaps. We recommend focusing the legislation on technology assistance rather than assistive technology. The focus on technology assistance will provide a mechanism to allow a wide range of services and research on the use of technology to assist persons with handicaps of all ages gain access to the advantages of technology for learning, living, working, and recreating. We propose the following definitions:

(A) Technology assistance means providing to individuals who have handicaps and/or disabilities any or all of the following:

(1) information about products which are electronically operated, including microchip-based and integrated telecommunication systems, and other products which assist persons with handicaps and/or disabilities to utilize electronially operated products;

(2) help in loating persons or public or private entities that can develop or modify such products to meet the needs of such individuals;

(3) help in establishing or locating support systems which facilitate the effective use of such products, including but not limited to needs assessment, prescription, and customization of the product(s) and training in procedures for using the product(s);

(4) help in finding funding sources that can be accessed to purchase such products;

(5) help in maintaining and upgrading such products;

(6) purchasing such products.

(B) Persons with handicaps and/or disabilities who could benefit from technology assistance are:

(1) persons who are eligible for special education and related services or early intervention services or early intervention services under the Education of the Handicapped Act; persons who are eligible for services under Titles I, VI, VII of the Rehabilitation Act; persons with rights under Title V of the Rehabilitation Act; persons who are eligible for assistance under Titles II and VI of the Social Security Act; and/or persons who are eligible for assistance under the Developmental Disabilities Act; and

(2) who could benefit from technological assistance which is likely to establish or improve their ability to function at home, in school, in the community, in recreational settings, on the job, and/or in other environments.

2. Many forms of technology enable individuals to communicate, learn, work, and recreate in a variety of new ways. When these advantages are limited to one setting, the power of the technology is greatly diminished both for the person and for the community. Therefore, any legislation must recognize and address the need for technology to be as transportable as possible so that persons can use it in as many situations as their life demands.

3. Technology is a powerful and robust tool that can assist persons regardless of age, type of severity or handicap. This breadth of application, however, creates problems in developing and implementing policies that foster responsible programs and services for a highly heterogenous population with diverse needs for technology assistance. Legislation must, therefore, respond on the one hand to the broad range of human needs that requires an array of frequently unique technology applications and on the other hand provide sufficient time and resources that will enable development and implementation of programs and services that responsibly serve a very diverse population.

4. There is a growing need for service delivery systems, either current or planned, to respond to requests for technology assistance. At the same time, that there is systemic response to the need (i.e., individuals have a clear entry point to technology services), the response must be designed for each individual, not standardized for all individuals.

5. Research and development are essential for the advancement of technolgoy and its application. To date, research has demonstrated that technolgoy can be a powerful learning tool. Additional research is required, however, to identify new technologies and to expand our knowledge about the application and integration of technology as a learning tool. As new technology emerges, we must develop and adapt applications for assisting persons with handicaps. Therefore, we strongly recommend

that any legislation contain provisions to authorize the state and federal governments the authority to fund competitively awarded research and development grants related to technology applications for persons with handicaps.

6. Education is lifelong. P.L. 99-457 has already expanded special education intervention to birth and transition programs are developing to assist persons moved from schools to the world of work. Society is moving from an industrial base to an information base illustrating that new knowledge and skills are necessary for maintaining a productive life. Therefore, this legislation must recognize the important role of education throughout the lifespan from birth to the grave.

7. While legislation should appropriately contain minimum criteria, it is essential, however, that the criteria be sufficiently flexible to accommodate variation among the programs and services offered by different states and the diverse and sometimes idiosyncratic technology assistance needs required by individual states.

8. Federal Role. The federal government has a number of critical roles it must play beyond helping states. We recommend that the federal government:

a. Coordinate and monitor common features among the states to reduce duplication of efforts (e.g., software resource guides).

b. Assist in the process of evaluating and certifying hardware and software products developed to provide technology assistance.

c. Fund competitively awarded grants to prepare personnel to assist in the development and delivery of technology assistance. There is a continuing need to prepare personnel to competently employ technology to assist persons with handicaps to learn, work, communicate, or recreate.

d. Fund competitively awarded grants to agencies to demonstrate exemplary applications of technology assistance and systems for delivering technology assistance services. The purpose is to foster the development of model programs and applications that can be replicated across states.

e. Fund competitively awarded research and development grants in the area of technology assistance. The purpose is to identify new technologies and to develop new technology applications.

f. Encourage through incentives private sector development and marketing of technology and technology products.

g. Not develop overly prescriptive regulations that provide a disincentive to private sector firms interested in developing and marketing hardware and software devices or technology assistance delivery systems. The private sector must be an ally in the development and creation of systems to deliver technology assistance to persons with handicaps.

9. The ultimate success of technology for persons with handcaps is dependent on their participation in the selection and adoption of the system. Consumers should be members of Advisory Councils and in other leadership and decision-making roles pertaining to the provision of technology assistance.

Mr. Chairman, we thank you for the opportunity to submit this statement and we stand ready to assist you and the Committee as you develop legislation on this most important issue.

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